

**Understanding friends and family members’  
experiences of going abroad with medical tourists**

**by**

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B.A.Sc., University of Lethbridge, 2010

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## **Abstract**

When patients privately obtain a medical procedure abroad they are engaging in medical tourism. Friends and family members often accompany medical tourists abroad to provide care, and are herein referred to as caregiver-companions. This thesis provides a broad understanding of caregiver-companions from an industry perspective. Interviews were conducted with medical tourism facility staff members who interact closely with caregiver-companions: International Patient Coordinators (IPCs). Twenty-one IPCs who work in nine countries were interviewed. Thematic analysis of these interviews resulted two analyses. The first examines the care roles taken on by caregiver-companions. The second examines the challenges that informal caregiving in medical tourism can present to medical tourists, facility staff, and caregiver-companions themselves. This thesis concludes that while caregiver-companions provide valuable care to medical tourists, with assistance from IPCs, they are not fully incorporated as caregivers in the medical tourism industry.

**Keywords:** Medical tourism, informal caregiving, international patient coordinators, qualitative analysis, international health care, family caregiver

*This thesis is dedicated to my family for their lifelong love, support and encouragement, and to my fiancé who has been an ongoing source of motivation and inspiration.*

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## **List of Acronyms**

SFU	Simon Fraser University
IPC	International Patient Coordinator

## Glossary

Medical Tourism	A multi-billion dollar industry whereby hospitals, clinics, and individual health care practitioners provide medical treatment to privately-paying international patients who travel to their facility from abroad without a formal cross-border care referral. Patients often pay for treatment out of pocket.
Medical Tourist	A person who obtains medical care abroad, outside of an established cross-border care arrangement, and usually pays out of pocket.
Caregiver-Companion	A friend or family member who accompanies a medical tourist abroad.
International Patient Coordinator (IPC)	These individuals work at medical tourism facilities and provide non-clinical, personal assistance to medical tourists. This assistance is primarily provided while the medical tourist is in the facility, and is usually also available before departure to the destination country, following discharge from the facility, and after return home. Although IPCs possess diverse job titles and responsibilities, they typically arrange transportation, create itineraries, and are available for questions or concerns from both medical tourists and caregiver-companions.
Informal Caregiver	A friend, family member, or community volunteer who provides unpaid care work, usually in the patient's home, beyond that which is offered by formal healthcare providers.
Ethics of Care	A theoretical framework that carries the assumptions that: (1) everyone is vulnerable to needing care, (2) therefore those who can provide care have a responsibility to offer it, (3) especially to those in need of care who feel comfortable being vulnerable around the potential care provider, and with whom the feeling is reciprocated.
Formal Health care Provider	Health care practitioners who receive specialized training specific to the care they deliver, are paid to deliver this care, and are commonly licensed professionals.
Medical Tourism Facility Staff	This encompasses everyone who works at the medical tourism facility including formal health care providers, IPCs, custodial staff, cooks, and technicians.
Medical Tourism Facility	Hospitals and clinics that specialize in the provision of medical treatment to medical tourists.



# 1. Introduction

People have travelled for health purposes since antiquity (Connell, 2011; Dvorjetski 2007; Elsner & Rutherford, 2010; Erfurt-Cooper & Cooper, 2009; Gesler, 1996). However, present day transnational healthcare is unique and is distinctly referred to as medical tourism. The global medical tourism business is a thriving industry that encompasses many socio-economic classes and nearly all countries as either destinations or countries of origin (Connell, 2013; Lunt et al., 2012). Medical tourism has all the catchments of a modern industry including financial incentives from and for governments, for investors, private companies, multilingual and highly skilled employees, and consumers (Connell 2006; Herrick, 2007; Hopkins et al., 2010; Ramírez de Arellano 2007; Terry, 2007). My investigation of medical tourism is limited to medical procedures that do not involve dentistry or a third party such as organ transplants and in-vitro fertilization. Nor do I consider international patient travel within established cross-border care arrangements, expats obtaining medical care in their country of residence, or tourists who organize a medical procedure while they are already abroad or who require emergency care while abroad. These mobile care practices are sometimes counted as medical tourism by those not familiar with the differences between them or those seeking to inflate the figures reporting on medical tourists' flows (Connell, 2013; Lunt & Carrera 2010; Terry, 2007).

My thesis looks at medical tourism through a health geography lens. Health geography is a sub-discipline of human geography, which emphasizes spatial research in the social sciences. Health geography “explores how and why people's health and access to health care vary from place to place” (McLafferty, 2010). This means that the scope of health geography research looks beyond that which is strictly clinical such as disease and encompasses, among other foci, social, physical, and emotional wellbeing, as well as the

accessibility of health care, both formal and informal, when these elements are askew (McLafferty, 2010; Jordan, 2012). My thesis intrinsically fits within the domain of health geography because it examines informal caregiving and caregiver health and wellbeing under a spatial lens. It contrasts the local space of care of conventional informal caregivers with the transnational one of caregiver-companions. My thesis complements the existing research on medical tourism by health geographers, which, though limited, looks at a variety of issues including: (1) health equity issues (e.g. Connell, 2011; Johnston et al., 2010; Ormond, 2013; Snyder et al., 2013); (2) the nature of the medical tourism industry (eg. Crooks et al., 2011; Johnston, et al., 2011; Lunt et al., 2012; Penney et al., 2011); (3) the health and safety risks to medical tourists and other medical tourism stakeholders (eg. Crooks et al., 2013); and (4) accessibility of perceived safe, high quality and timely healthcare in home countries compared to accessibility abroad (eg. Migge & Gilmartin 2011).

My thesis makes a novel contribution to the health geography scholarship on medical tourism through its consideration of the practice of informal caregiving in this global health services practice. Informal caregiving is a topic that has garnered significant attention by health geographers (eg. Herron & Skinner, 2012; Milligan, 2009; Wiles, 2003; Williams et al., 2003), though not within a transnational care context. Furthermore, I believe that studying medical tourism from a health geography perspective fills an important niche in that the bulk of scholarly work in this field focuses on clinical, legal, and economic aspects of medical tourism (e.g., Chan et al., 2011; Connell, 2013; Lunt & Carrera 2010; NaRanong & NaRanong, 2011; Terry, 2007).

In the section that follows, I provide an overview of the practice of medical tourism and the scholarly debates that have emerged about this globalizing industry. Following, a review of the existing knowledge on informal caregiving in medical tourism is presented. As I noted above, the practice of informal caregiving within medical tourism - that is, the care that is given by friends and family members who accompany medical tourists abroad - serves as the focus of my research. These caregivers will be

referred to as caregiver-companions throughout the thesis. I conclude this chapter with a study overview and an introduction to the remaining thesis chapters.

## **1.1. Background on Medical Tourism**

Medical tourism is a nascent industry, but it is already a global presence. Some Global South countries have an established norm of obtaining health care abroad because social pressure, norms, or prestige push these patients abroad to obtain foreign medical care (Kangas, 2011). Other countries are accustomed to accommodating these and other medical tourists and have been doing so for decades (Horowitz, et al., 2007; Turner, 2007a). Despite these well established patient flows, it was not until the sizeable movement of patients from Global North to Global South countries began that this practice of seeking private medical care abroad came to be known as ‘medical tourism’ (Burkett, 2007, Turner, 2007a).

Several medical tourism destination countries with established industries, such as India and Thailand, are becoming increasingly more entrenched in the industry with projected economic growth (Herrick, 2007; Lundt et al., 2012; NaRanong & NaRanong, 2011; Sobo, 2009). Furthermore, countries that were not previously involved in the industry are entering it (Connell, 2006; Snyder et al., 2013) or are considering doing so. Belize, for example, recently obtained the support of local physicians in its discussion to introduce the industry within its borders (International Medical Travel Journal, 2012). Allied industries such as the travel and tourism sector are also growing in countries with booming and nascent medical tourism industries alike (Connell 2013; Lundt et al., 2012). Job creation continues to increase in many popular destination countries as the industry grows (Sobo, 2009; Turner, 2007a). As the hallmark of any industry, financial growth is indicative of the importance of medical tourism.

Growing amounts of research is dedicated to understanding patients’ motivations for engaging in medical tourism. These motivations can vary according to each individual’s circumstances. Patients residing in countries where procedures are only



available after lengthy wait-times may wish to obtain procedures sooner by going abroad (Eggertson, 2006; Johnston et al., 2012). Patients may also choose to engage in medical tourism when the desired procedure is only available abroad (Connell, 2013) because it is too new and/or difficult to be offered domestically (Horowitz, et al., 2007; Johnston et al., 2012; Turner, 2012). This is sometimes referred to as ‘circumvention tourism’ if the procedure is illegal in the home country (Cohen, 2012). Cost savings is also frequently cited as a motivation to obtain healthcare abroad among those who are either un/underinsured or who wish to obtain a procedure for which they would need to pay for out-of-pocket at home (Burkett, 2007; Horowitz, et al., 2007; Johnston et al., 2012; Turner, 2007a). Others choose to obtain a medical procedure abroad because of familiarity with the destination country (Lee et al., 2012; Lundt et al., 2012; Migge & Gilmartin, 2001). In sum, there are many reasons for which a patient will choose to obtain a procedure abroad. Multiple reasons can play out at different times in the decision-making process (Johnston et al., 2012), and these are each tied to the patient’s individual circumstances.

Certain ethical and equity concerns have been raised regarding the medical tourism industry. Public health care sectors in destination countries, for example, may suffer from shortages of formal health care workers, especially in rural areas (Connell, 2013; Hopkins et al., 2010; Johnston et al., 2010; Lundt et al., 2012). Formal health care providers in these countries, including physicians, are consistently drawn away from the public sector and towards private medical tourism facilities because they can draw a higher salary in the latter and work in more advanced facilities (Hopkins et al., 2010; Johnston et al., 2010; Lundt et al., 2012). Some governments have taken steps to slow this internal brain drain. Regulations, including mandatory placement of new graduates in rural areas (Martínez & Martineau, 2002; Wibulpolprasert & Pengpaiboon 2003) and focused recruitment, training, and retention in rural areas have also been initiated in Thailand and India. Monetary and artificial prestige incentives are also offered to physicians working in rural regions in Thailand (Pachanee & Wibulpolprasert 2006). However, these regulations and incentives may not be effective or diligently enforced. The depletion resources for the public health care sector in some destination countries is

amplified by government subsidies for medical tourism facilities as an investment in their financial growth (Hopkins et al., 2010; Johnston et al., 2010; Lundt et al., 2012). These are funds that may have otherwise been allocated to the public sector.

Equity and ethical concerns exist for medical tourists' home countries. Although all surgical procedures expose patients to infection, the type of infection may vary depending on the global region in which the surgery is obtained. There is, then, a risk that medical tourists can bring home an infection that is both foreign and contagious, and which the home health care system may be ill-equipped to handle (Canales, et al., 2006; Chan et al., 2011; Crooks et al., 2013; Johnston et al., 2011). More commonly, patients can return to their home countries with surgical complications that require treatment (Birch et al., 2010; Canales et al., 2006; Crooks et al., 2013; Johnston et al., 2011). In countries with public health care systems, this presents an ethical conundrum: since the patient elected to obtain a medical procedure outside the public health care system, is it the system's responsibility to shoulder the financial burden of offering care for the resulting complication? This is an unresolved point of contention in some countries such as Canada (Birch et al., 2010; Johnston et al., 2011; MacReady, 2007). In the same vein, should home physicians be responsible for ensuring the continuity of care for patients who went abroad to obtain a procedure? Clear and comprehensive records are not always available from medical tourism facilities, which discourages some home physicians from offering follow-up care for fear of liability (Crooks et al., 2013; Hutson Gray & Cartier Poland, 2008; York, 2008). There is also discussion of integrating medical tourism in the established healthcare system for cost-saving reasons (Birch et al., 2010; Herrick, 2007; Sobo, 2009). For patients' home countries, medical tourism brings up ethical and equity questions that involve many stakeholder groups, including patients, physicians, and taxpayers as funders of public health care systems.

## **1.2. Informal Caregiving in Medical Tourism**

Although medical tourism has drawn notable attention from researchers, there remain significant knowledge gaps. For example, the academic literature often ignores or only peripherally mentions the friends and family members who accompany medical tourists abroad, here referred to as caregiver-companions. For example, Lunt et al. (2012) mention caregiver-companions incidentally while discussing destination country profit from expenditures. Such references imply that caregiver-companions are taken for granted as part of the medical tourism experience. Kangas (2007), meanwhile, interviewed caregiver-companions as witnesses to the hardships experienced by Yemeni patients who went abroad for necessary but largely unaffordable health care. Once again caregiver-companions are treated incidentally rather than as active stakeholders in medical tourism. NaRanong and NaRanong (2011) offer an estimate of the financial cost that accompaniment by a caregiver-companion can add to a medical tourist's budget. The article states this very briefly without providing reasons for which this additional expense may be justifiable. Through this academic research, it can be surmised that caregiver-companions accompany medical tourists often enough to be taken for granted rather than treated as an exception. It is also reasonable to assume based on this literature that they are present through much of the medical tourism experience and are often perceived by medical tourists as worth additional expense. Non-academic sources concur with these surmises (e.g., Grace, 2007; Medical Tourism Association, 2009; Rose 2009; Travers et al., 2008) but they lack the necessary rigor of academic literature to be considered credible documents that can inform policy or other types of interventions.

A previous study undertaken by my research group found that caregiver-companions adopt caregiving roles towards medical tourists (Crooks et al., 2011). This finding is concurrent with the non-academic sources that discuss this medical tourism stakeholder group (Grace, 2007; Kingsbury et al., 2012; Rose, 2009). According to these sources, caregiver-companions have similar roles and responsibilities to traditional informal caregivers who care for ill or dying friends or family. Like other informal caregivers, it seems that caregiver-companions interact with formal health care providers

as monitors, assistants, advocates, and learners (Donelan et al., 2002; Petronio et al., 2004; Sinding, 2004; Weinberg et al., 2007). They also offer provide support for daily activities and some degree of care coordination (DeGeest et al. 2003; Donelan et al., 2002; Grace, 2007; National Alliance for Caregiving & AARP, 2004; Rose, 2009; Weinberg et al., 2007). The key difference between other informal caregivers and medical tourists' caregiver-companions is that the latter group provides care in a transnational context. They travel with the patient from their home country and back, and in doing so provide care across, in, and through a number of places, including the airport, the home, the hospital, and the hotel. This transnational dynamic serves as a key backdrop for my thesis research.

My thesis is the first academic study to put a 'spotlight' on caregiver-companions, who constitute a previously neglected medical tourism stakeholder group in the ever-growing global medical tourism industry. Because caregiver-companions are frequently at the medical tourist's side, I believe they have the potential to inform the quality of the patients' experience abroad and thus ultimately their health. Furthermore, it is likely that caregiver-companions are exposed to some risks through their caregiving roles, but attention to mitigating these risks will not be given without the recognition of their importance and value of as a stakeholder group. It is for these reasons that the knowledge gleaned from my thesis is both timely and important.

### **1.3. Study Overview**

This thesis has two objectives, which are to: (1) explicate how caregiver-companions balance multiple roles and responsibilities; and (2) determine the health and safety risks to which caregiver-companions may be exposed through the process of transnational caregiving. Several approaches could be used to address these objectives. Liberal individualism looks at individuals, but it prioritizes them over relationships and denies selfless collaboration; this complicates the subject of the study which is the unpaid caregiving of loved ones. An ethics of justice approach emphasizes fairness and rights, in

which informal caregiving fits quite well, but it is effective at the societal scale rather than the individual one on which I want to focus (Held, 2006). This thesis is instead framed around an ethics of care methodological framework. According to the framework, every individual has the right to be cared for when they need it because all individuals are at risk of needing care at any time (Held, 2006; Parton, 2003; Tronto, 1993). Consistent with this, I approach this research from the assumption that everyone is vulnerable to illness, disability or pain that requires care beyond the scope of formal health care providers. I also assume that everyone has the right to this required care. For these reasons, a third assumption is made: it is, in turn, the responsibility of close others to provide this care to someone in need of it. This does not mean that all healthy people must provide help to all unhealthy people. An ethics of care approach applies only to those in need of care who feel comfortable being vulnerable around the potential care provider, and to those who can provide care while confronting this vulnerability as well as their own (Beauchamp & Childress, 2001; Parton, 2003). I thus conceive of caregiver-companions as being mandated to provide care to the medical tourists they accompany.

This thesis contributes to a larger study funded by the Canadian Institute of Health Research (CIHR) that aims to establish an understanding of the experiences of Canadian caregiver-companions. The two analyses pursued in the following chapters work towards addressing this aim. In these analyses, I seek to establish a broad foundational understanding of medical tourists' caregiver-companions by gathering the perspectives of those who interact with them closely in a professional capacity while they are abroad; although their job titles vary, they are collectively referred to as international patient coordinators (IPCs) throughout this thesis. IPCs work at medical tourism destination facilities and take on a number of non-medical responsibilities related to the travel, transportation, support, and care for medical tourists. I focus on this group because an individual IPC interacts with between a few dozen to more than one hundred caregiver-companions every year, which enables them to infer trends among this group.

In 2012, I conducted phone and Skype interviews with 21 IPCs working at 16 different medical facilities in nine countries. Following SFU Research Ethics Board

approval, I recruited IPCs using a variety of methods including email and advertisement. Potential participants were screened for eligibility, and those who were eligible were sent a letter containing study information. A phone or Skype interview was scheduled thereafter. Following the interview, an honorarium was sent to participants to acknowledge their participation. Following completion of data collection and in conjunction with the other study investigators, I coded and analyzed the interview data thematically. Two analyses were pursued using the coded data, one that investigates the main roles that caregiver-companions play and the other that examines the challenges posed by caregiver-companions from an industry perspective. These analyses form the basis of this thesis and are presented in the following two chapters along with a more expanded discussion of the study methods.

## **1.4. Thesis Outline**

The next two chapters, Chapters 2 and 3, were each written with the intent of publication in academic journals. Drawing on interviews with IPCs, Chapter 2 examines the roles and responsibilities that caregiver-companions were found to adopt while abroad, as well as before and after the trip. The chapter thus presents the usefulness of caregiver-companions and identifies their place among other medical tourism stakeholders. By fleshing out caregiver-companions' roles, and in doing so identifying some of the care responsibilities they take on, the previous lack of understanding of caregiver-companions is highlighted and further research into the means of integrating them more effectively as medical tourism stakeholders is invited.

Again drawing on the IPC interviews, in Chapter 3 I explore the challenges that the presence of caregiver-companions can pose to other medical tourism stakeholder groups, namely medical tourists and medical tourism facility staff. Discussed from an industry perspective, the chapter highlights the burdens and disruptions that caregiver-companions can introduce, as well as the ways in which they can create additional stress

for hospital staff, medical tourists, and for themselves. The chapter demonstrates that caregiver-companions are likely not sufficiently integrated into the medical tourism industry despite their pervasiveness. It reveals that, as a stakeholder group, they require more consideration from industry members including those in destination facilities.

Chapter 4 concludes the thesis. In this chapter, I explore the research contributions of the analytic chapters. The research presents: (1) an acknowledgement of the value of conducting interviews with third party stakeholders, in this case IPCs, in order to advance knowledge about medical tourism; and (2) an example of the successful application of geographic concepts to health research using an ethics of care framework. Future research steps are discussed following this. Finally, I conclude by reiterating the importance of caregiver-companion research and by acknowledging caregiver-companions as an important stakeholder group.

## **2. Knowledge Brokers, Companions, and Navigators: Informal Caregivers' Roles in Medical Tourism\***

### **2.1. Background**

Health care delivery involves many provider groups, both formal and informal, that address different facets of patient care. Doctors and nurses are examples of formal provider groups in that they receive specialized training specific to the care they deliver, are paid to deliver this care, and are commonly licensed professionals (Martin, 2010; Smeltzer et al., 2010). Much social health research has documented the important and complex responsibilities that formal providers assume in ensuring patients' health and general wellbeing (eg. Schein et al., 2005; Schoenborn et al., 2013; van Bruchem-van de Scheur et al., 2008). In contrast, informal health care providers include friends, family, and some volunteers. Members of these groups provide essential care despite the fact that they are not formally trained and paid health professionals (Connor, 2003; Karimli et al., 2012). These informal care providers, or caregivers, often provide ongoing essential care in the home, such as administering medications, managing wounds, and assisting with rehabilitation (Ussher et al., 2011). Meanwhile in hospitals and other types of residential care settings, they perform tasks that augment services provided by on-site formal providers. Examples of such tasks include monitoring symptoms and articulating patients' preferences to health care professionals (Halvorsen et al., 2009; Lam, 2006; Sinding, 2004). The roles that formal and informal providers fill and the responsibilities

\* Casey, V., Crooks, V.A., Snyder, J., & Turner, L. (2013). Knowledge brokers, companions, and navigators: Informal caregivers' roles in medical tourism. Manuscript submitted for publication.



assigned to each collectively work together to enable health care delivery. In this article, we examine the caregiving roles assumed by a specific group of informal health care providers: the friends and family members who accompany medical tourists abroad for private medical care.

Hospitals, clinics, and individual health care practitioners who provide medical treatment to privately-paying international patients who do not have a formal cross-border care referral are part of what is often described as the ‘medical tourism industry’ (Connell, 2013; Ehrbeck et al., 2008; Lunt et al., 2012). This industry is reported to be on a multi-billion dollar scale and involves the transnational movement of patients to a growing list of destination countries located on nearly every continent (Deloitte Center for Health Solutions, 2008; Ehrbeck et al., 2008; NaRanong & NaRanong, 2011; Pocock & Phua, 2011; Tourism Research and Marketing, 2006). There are a great variety of procedures that can be obtained through medical tourism including, though not limited to, cosmetic surgeries, cardiac surgeries, and orthopedic surgeries (Alleman et al., 2011; Burkett, 2007; Deloitte Center for Health Solutions, 2008).

Research examining medical tourism has paid some consideration to numerous health care provider groups central to this global health service practice. Perhaps not surprisingly, much of this research examines formal health care providers rather than informal ones, though sometimes members of the latter category are mentioned in passing. Although academic studies and industry reports note that it is common for medical tourists to be accompanied by friends and family members (e.g., Connell, 2013; Kangas, 2007; NaRanong & NaRanong, 2011; Yeoh et al., 2013; Yu & Ko, 2012), they are rarely framed as informal health care providers or as subjects meriting additional exploration. Meanwhile, it is widely acknowledged that informal caregivers provide the bulk of patient care throughout the life course and across the care continuum and play an important role in establishing care recipients’ health outcomes (Bevan & Pecchioni 2008; Karimli et al., 2012; Molloy et al., 2005). Given the importance of informal caregivers in health care provision, it is surprising that their contributions to the care of medical tourists have not attracted greater scrutiny. Only non-academic work has addressed the

practice of informal caregiving in medical tourism. Two published narratives of medical tourists' journeys written by their informal caregivers reveal that significant caregiving responsibilities were assumed by these individuals (Grace, 2007; Rose, 2009). Their detailed narratives document numerous instances of making decisions on behalf of the patient, liaising with formal providers, coordinating appointment scheduling, offering hands-on care, providing emotional and spiritual support, and taking responsibility for managing care-related finances. These narratives, although not intended as contributions to health research, are nonetheless illuminating because they suggest that informal providers can play a significant role in the practice of medical tourism. In this article, we aim to identify and explicate the informal caregiving roles that friends and family members assume in the course of a medical tourist's journey. By 'roles' we refer to their key social functions in the maintenance of medical tourists' health and wellbeing and the larger transnational care practice of medical tourism.

Our exploration of informal caregivers' roles herein is informed by insights gleaned from interviews with International Patient Coordinators (IPCs) working at medical tourism facilities. IPCs work at destination facilities; their task is to coordinate medical tourists' care. Their responsibilities include arranging ground transportation and local travel, communicating with doctors, scheduling medical appointments, and providing support and guidance for patients and their caregivers. Because of the nature of their jobs, every year they interact with anywhere from tens to hundreds of medical tourists and their informal caregivers. Given their function, we believe that by sharing their observations and experiences they are well positioned to identify the informal care roles filled by this caregiver group. In the section that follows we provide an overview of the study design and a description of the 21 IPCs with whom we spoke. We then present the findings of a thematic analysis that identified three roles commonly filled by medical tourists' informal caregivers: knowledge broker, companion, and navigator. We subsequently discuss the findings in light of the existing medical tourism and informal caregiving literatures and offer directions for future research.

## **2.2. Methods**

This article emerges from a large, multi-method study that explores first-hand accounts of medical tourists' informal caregivers and those who have worked closely with them in a professional capacity. Here, we report on the findings of interviews conducted with IPCs about their interactions with and observations of these caregivers. The findings speak to the roles filled by caregivers from a range of home countries as they accompany medical tourists seeking a variety of medical procedures at international health care facilities worldwide.

### **2.2.1. *Participants***

IPC recruitment commenced after receiving approval from the Research Ethics Board at Simon Fraser University. We sought participants from a diverse range of countries and facilities using several concurrent methods: (1) emailing letters of invitation to hospitals and clinics whose websites mentioned IPCs, IPCs identified in online medical tourism directories, and IPCs who had posted on online forums; (2) snowballing out from initial participants; and (3) disseminating calls for participants through our team's networks and online medical tourism industry forums and magazines. Recruitment materials indicated that interviews could be conducted in English or French. A later request for a Spanish-language interview was also accommodated.

Interested potential participants who contacted us by e-mail were sent an information sheet that provided additional information concerning the study and described their rights as participants. Before this sheet was sent, participant eligibility was confirmed. Because many potential participants did not use 'IPC' as their official job title, they were required to indicate that: they worked with international patients who obtained procedures at medical tourism hospitals or clinics that offered surgical procedures without third party involvement such as organ transplantation; they were physically present in the facility with the medical tourist; they made care and other arrangements; and they assisted clients in a non-clinical capacity. To capture diversity

among the sample, no more than 3 individuals from a single facility were interviewed. We stopped active recruitment and interviewing when we reached our target sample size of 20, a point that coincided with when new potential participants were no longer being identified.

Twenty interviews were conducted with 21 IPCs (one interview had two participants) who drew from their experiences working at medical tourism hospitals or clinics in Bolivia, Costa Rica, Barbados, Mexico, the United States, Croatia, Turkey, Israel, India, and Thailand. Participants worked at 16 different facilities across these countries. Twelve IPCs mainly dealt with North American medical tourists, six mostly serviced Europeans, one primarily saw Australians and another Africans, and the remaining two did not report a particular regional orientation. The procedures provided at the facilities where the participants worked included cosmetic surgery, bariatric surgery, orthopaedic surgery, oncology procedures, spinal surgeries, veinoplasty, and cardiac surgery.

### **2.2.2. *Data collection***

Interviews were conducted over telephone or Skype according to the participant's preference. They typically lasted for 45-75 minutes. A semi-structured interview guide was used, enabling the capture of issues central to the study's objectives and topics that were important to the participants. The first author conducted 19 English-language interviews and a knowledgeable collaborator conducted one in Spanish. No French-language interviews were requested.

Verbal consent was obtained before each interview. The interviews covered topics such as: (1) informal caregiver characteristics, (2) interactions between caregivers and medical tourism facility staff, (3) caregivers' roles and responsibilities, and (4) the risks to which caregivers can be exposed while travelling with medical tourists and providing care to them.

### **2.2.3. Analysis**

All interviews except one were recorded digitally and transcribed verbatim. Technical difficulties prevented the exception from being recorded, and detailed interviewer notes were instead used to document the interview. All transcripts and notes were loaded into NVivo, a qualitative data management program, after which thematic analysis was conducted.

The thematic analysis involved six steps. First, all investigators reviewed the transcripts and notes. Second, emerging themes and outliers were identified during a face-to-face meeting with all investigators. Third, the first and second authors created a preliminary coding scheme that identified overall thematic concepts and their components. Fourth, the first author coded the data in NVivo, with input on code refinement and interpretation from the second author. Fifth, the first and second authors identified emerging trends and patterns relevant to the themes pursued in this article, namely those pertaining to caregivers' roles. Sixth, a refined interpretation of meaning in the coded data was revealed through a comparison of the trends and patterns with existing knowledge and the study objectives (Fereday & Muir-Cochrane, 2006). This comparison was initially done by the first and second authors and then confirmed by the full team. Characteristic of thematic analysis, this analytical process enabled common themes to emerge despite the differences in IPC participants' work environments and work histories (Braun & Clarke, 2006).

## **2.3. Findings**

All IPCs reported that it was common for medical tourists to bring at least one friend or family member abroad with them unless they were specifically discouraged

from traveling with a companion<sup>\*</sup>. Family members, especially spouses, were the most common type of informal caregivers present at the facilities where participants worked. Facilities that offered in-patient procedures often had cots or beds available in patients' rooms for these informal caregivers. This arrangement demonstrates the intense physical proximity of this transnational caregiving practice. Figure 1 provides an example of this kind of patient room. In the case of out-patient clinics or where co-habitation in the patient's hospital room was uncomfortable or impossible, friends and family typically stayed at nearby hotels or rented apartments.

<sup>\*</sup> Informal caregivers to patients recovering from cosmetic or bariatric surgeries were sometimes noted to be problematic to patients' wellbeing because they can become visibly distressed by a patient's appearance. Therefore, some IPCs who worked at facilities specializing in these procedures advised medical tourists to travel unaccompanied.

**Figure 1.**

***Shared space between the medical tourist and informal caregiver***



Note. Taken at hospital in India that treats medical tourists, this photo conveys the close physical proximity that is experienced between some medical tourists and their informal caregivers while abroad. The cot on the left is for the friend or family member providing care while the bed on the right is for the patient. (Photo credit: authors)

Thematic analysis of interviews conducted with 21 IPCs about their interactions with and observations of medical tourists' informal caregivers revealed three roles commonly adopted by this group: (1) knowledge broker, (2) companion, and (3) navigator. The knowledge broker role refers to key functions undertaken by caregivers around the transfer of information between the medical tourist and facility staff or others. The companion role refers to functions around the provision of emotional and physical comfort or support as well as hands-on care. Finally, the navigator role encompasses functions dealing with information gathering and care coordination responsibilities assumed by medical tourists' informal caregivers. Although IPCs observed that many

caregivers adopt all three roles, often simultaneously, we consider them separately in this section to provide detailed accounts of the distinct features of each role. We include verbatim quotations throughout to ‘give voice’ to the participants. Each quotation is followed by a country name, which indicates the country in which the participant worked as an IPC, and a number, which indicates the number of years he or she had been working as an IPC at the time of the interview.

### **2.3.1. Knowledge Broker**

Participants emphasized that a key role caregivers play is that of knowledge broker. The facilitation of knowledge transfer from medical tourism facility staff to the patient by caregivers is typically done in four ways: inquiry, clarification, translation, and retention. First, caregivers commonly make inquiries on behalf of patients. Questions directed toward IPCs tend to be about logistics or planning, whereas those directed at formal providers cover clinical concerns such as prescriptions, care options, and advice for after discharge. Second, by seeking clarification caregivers help to ensure that patients clearly understand medical information. This activity can be especially helpful when patient rights are explained, when complications occur, or when patients are confused about what they have been told. Third, caregivers help with translation or basic communication when they are more proficient than the patient in the language or regional vernacular used by facility staff. *“When the patient comes over here, the language may differ or the accent may differ, [the understanding of] English between the patient and the [facility] staff may differ slightly, so there needs to be someone who can patiently communicate with the [facility] staff [if the patient cannot]”* (India, 2.25). Finally, caregivers retain information that has been conveyed by facility staff to the patients, such as meal details. *“Sometimes when you’re in that position [as a patient], you’re ill, you’re in a bed, the doctor comes in and says x, y or z, you don’t remember it... So it’s nice to have someone there with you who will be able to retain that information”* (Barbados, 2). Knowledge brokering by facilitating the transfer of information from facility staff to patients can be demonstrative of collaboration between caregivers and formal providers and other facility staff.



Caregivers often engage in knowledge brokering by offering unprompted but useful information about medical tourists to facility staff. IPCs noted that caregivers frequently offer this kind of information while patients are at the facility and also following discharge. For example, caregivers voice patients' concerns or articulate complaints when patients are reluctant to make such remarks. They also help formal providers obtain correct information when patients are untruthful (e.g., purposely not reporting their correct weight), do not accurately recall their health history, or are unwilling to communicate. For example, one participant reported that she once worked with a patient who was uncommunicative and therefore the accompanying caregivers answered her questions instead: "...sometimes the patient didn't feel like talking and then his mother or his wife would give me the information" (Mexico, 3). These types of information exchanges between facility staff and caregivers, ones that are not prompted by the medical tourist and might not occur in the patient's presence, reveal "...the good, the bad, the ugly, everything [about the patient that might be helpful to facility staff]" (Costa Rica, 2.5). In other words, caregivers might broker information or share details with facility staff to ensure that they have accurate information with which to make decisions that affect patients' health independent of requests to do so from medical tourists.

Participants observed that caregivers often act as information liaisons between patients and friends and family members back home. They provide friends and family members with updates by phone, email, Skype, and even letters. One participant recounted that caregivers commonly "*bring their computer [or] they can borrow our telephones and right after the surgery they... communicate with people from home just to let them know that everything went okay*" (Mexico, 3). Acknowledging the importance of this aspect of caregivers' roles, some of facilities even offer them free international calling. This dimension of knowledge brokering serves to underscore the truly transnational nature of the roles that caregivers take toward medical tourists as well as within the larger practice of medical tourism.

### 2.3.2. Companion

One way that informal caregivers engage in the companion role is by creating a feeling of emotional safety and security for the medical tourist. A participant reported that caregivers provide “...*emotional support, which was probably the most crucial [thing that they can do]. It’s something that a medical tourism company cannot offer*” (Turkey, 1.5). Caregivers are familiar to patients, they have established relationships with one another, and bonds of trust already exist before their journeys begin. These traits put them in a unique position to offer intensely personal types of support, including moral and spiritual, relative to facility staff. Caregivers’ trusting relationships with medical tourists often makes them aware of patients’ preferences and needs. All the IPCs with whom we spoke indicated that trusting relationships between patient and caregiver can have emotional benefits for the medical tourist and that this social bond is a significant reason why they encourage medical tourists to avoid travelling alone. To a medical tourist, a caregiver is “*someone there who would be able to share your... experience... you wouldn’t have to... be looking for words, you would just be able... to flow with this person because this is someone that you know, it’s someone you have a history with, so you’d be more comfortable*” (Barbados, 2). According to the participants, the presence of the caregiver can be beneficial to creating a feeling of safety and security for the patient.

Many participants noted that caregivers typically try to address medical tourists’ comfort in their role as companions. This assistance comes in the form of: providing the patient with wanted or needed items, monitoring symptoms, and helping the patient deal with the ‘foreignness’ of the destination country. IPCs commonly observed caregivers obtaining items for the medical tourist inside and outside the facility because, participants postulated, they were more comfortable asking their companion than the IPC. For example, patients who dislike the food served at the facility can send caregivers into the surrounding area on regular food purchasing trips. To ensure physical comfort, nearly all participants noted that caregivers monitor patients’ symptoms and alert formal providers of noteworthy changes. A participant explained “...*we provide them with our extension*

*numbers and they might call us just to say ‘...my wife is having nausea after the operation, do you think somebody can give her some medicine’. So we do quite often see that situation.”* (Thailand, 6). Caregivers can further ensure patients’ comfort by being a familiar, reliable figure in an otherwise unfamiliar environment. IPCs explained that being outside one’s own country can be inherently stressful. Language differences in particular can be especially difficult for the patient. Patients and caregivers *“really just have each other . . . I mean the outside world speaks a different language, different culture. They rely a lot on each other”* (Turkey, 1.5).

Many participants reported that caregivers commonly provide hands-on care, especially after the patient is discharged from the facility. This care can take the form of assistance with mobility and everyday tasks and help with following clinical advice. Patients’ mobility and their capacity to perform everyday tasks after surgery are typically minimal, and therefore some facilities require that medical tourists bring a caregiver to assist them with daily activities following the operation. Caregivers often help patients with dressing, showering, toileting, and mobility at the facility and after discharge. After discharge *“...patients... might need the help of a companion with luggage, with getting in and out of a vehicle, perhaps getting up to their hotel room, go out to dinner, things like that”* (USA, 8). Caregivers also help patients follow clinical advice such as taking medications, sometimes offering hands-on care to ensure this advice is followed. One participant explained that caregivers need to know *“what not to do [when caring for the patient]: do not . . . bend the knee over this position if he has a knee replacement, or do not give him anything to eat besides what the doctor says if he has a gastric sleeve...”* (Costa Rica, 0.6). In some cases, caregivers continue this aspect of their companionship role after returning to their home country, ensuring appropriate post-operative and follow-up care regimens are followed.

### **2.3.3. Navigator**

Caregivers fill a navigator role when they guide the patient through various aspects of the medical tourism experience. One such aspect is geographical and cultural

navigation. For example, caregivers typically gather tourist information. As mentioned above, they can do this by asking facility staff, especially IPCs, questions about particular destinations in the local area. Some of these questions pertain to tourist activities that are suitable for the patient after discharge. Caregivers also seek location-specific information from IPCs, such as “*how to take a taxi and . . . what areas are safe to go to and what aren’t...*” (Mexico, 12). In addition to gaining familiarity with navigating the destination country or city, caregivers typically learn how to navigate the destination facility and transmit this information to the medical tourist. According to one participant, caregivers are “*the ones who read through the instructions [about the facility] and enforce them [with the patient]...*” (Mexico, 1.5, 0.6). Participants also noted that, in their capacities as navigators, all caregivers familiarize themselves with useful locations in the facility such as bathrooms and magazine vendors.

Most participants observed that a large part of a caregiver’s navigator role involves coordinating paperwork and gathering required documentation. “*Usually the companion, to relieve the patient that’s having the surgery, does all the running around to make it happen*” (Costa Rica, 5). Many IPCs reported that completing paperwork is one of the first tasks that caregivers must undertake after arriving at the facility. This task requires completing forms for the patient and verifying that patient information is accurate. They also “*...tend to want to deal with the finances... they’re always very worried about [the patient] being worried about... the balances or the costs that their stay incur. They tend to want to shield [the patient] from that*” (Barbados, 2). They typically monitor and complete financial paperwork, and might access a bank in person or electronically to exchange currency, to ensure funds are available, and to get money for airfare, treatment, and other expenses. Caregivers also commonly transfer documentation from the facility abroad to patients’ regular physicians and vice versa before departure and after return home. These documents include medical records, letters, prescriptions, and/or test results. IPCs remarked that navigating the coordination of paperwork and documentation is generally done by caregivers to minimize the number of concerns or stressors that medical tourists encounter.

Creating plans and ensuring that travel itineraries are followed are both common responsibilities for caregivers in their roles as navigators. Caregivers sometimes play a large role in preparing for the trip abroad. They communicate with IPCs to organize the trip, sometimes as early as sending the initial inquiry. They continue to fill this role throughout the stay by arranging lodging, tours, and food options. They also help patients by arranging ground transportation and international flight arrangements. “...They get the wheelchair for them and, you know rent a chair car to transport the patient to and from the hotel...” (USA, 8). Caregivers also sometimes create itineraries with the help of IPCs, and typically ensure that these plans are followed by the medical tourists. A key reason for this is because medical tourists typically look to caregivers “for [information about] the whole journey, you know: ‘What time are we going to the doctor? What time is our appointment? What time is the check-up? When do we go next? Tomorrow’s a day off, are we going touring? Are we going to the beach? Are we going shopping?’” (Israel, 3). Caregivers know the estimated length of the patient’s stay in the facility and note changes in the recovery schedule after surgery so that they can alter or cancel activities as needed. Even after they are back in their home country, caregivers often help patients create and follow an itinerary of follow-up appointments. The majority of participants noticed that caregivers generally help patients navigate their experience abroad by making and altering plans as needed, and that nearly all of them play an important role keeping patients on schedule.

## **2.4. Discussion**

The analysis has found that medical tourists’ informal caregivers adopt three major roles that complement those of formal health care providers: knowledge broker, companion, and navigator. As knowledge brokers, they facilitate the transfer of information between the medical tourist and the formal health care providers, the IPC, friends and family members back home, and others. As companions they support the medical tourist emotionally by ensuring their comfort and providing hands-on care. Finally, in their role as navigators they gain familiarity with the destination country,

coordinate the trip, and handle facility documents. In this section, we examine interconnections between these roles and consider all three in light of the existing medical tourism and informal caregiving literatures. We also identify future directions for research emerging from the findings.

Each of the three caregiver roles identified by IPCs encompass several responsibilities. Many responsibilities are unique to a single role. Handling finances, for example, which is part of the navigation role, has no overlap with other role components, though the outcomes of this responsibility might have implications for caregivers' other roles. Other responsibilities might seem less clearly delineated with regard to the roles to which they contribute because of the similarities of the activities they involve. For example, there are information exchange aspects to all the roles. The difference is the intermediary or primary position of the caregiver in the exchange and the nature of the information. Offering or retaining information on behalf of the patient is characteristic of the knowledge broker role. Meanwhile, flagging the patient's changing health status to staff relates most closely to the companion role, whereas discussion about travel logistics relates to the navigator role. By both focusing on the intent of an action being undertaken and identifying the scope of each role, it was clear in the analytic process which responsibilities were attributed to what roles.

A strong relationship exists between the caregiver roles because the actions, activities, and overall responsibilities undertaken in one role can have implications for the other two roles. In this way, there is overlap between all the roles identified in the findings. By helping patients follow clinical advice, which pertains to the companion role, caregivers act on advice they might have retained in their capacity as a knowledge broker. When the clinical advice requires arranging medical appointments and ensuring that patients arrive at appointments in a punctual manner, then there is also overlap with the navigator role. Knowledge brokering and the companion role further overlap when caregivers monitor medical tourists' symptoms and communicate those observations to a health care provider; symptom monitoring is identified as part of the companion role, whereas voicing comments or concerns about symptoms to formal providers is part of the

knowledge broker role. These are but a few of the many examples of the ways that distinctive roles become interconnected through the practice of informal caregiving in medical tourism. Although these interconnections can create some overlaps or redundancies between roles, we believe that the distinctions between the knowledge broker, companion, and navigator roles remains useful for clearly positioning the friends and family who accompany medical tourists abroad as informal caregivers, and ultimately unpaid health care providers, within the industry.

Although the existing medical tourism literature does not discuss informal caregivers' roles in detail, there are some mentions of the same activities or responsibilities that were discussed by the IPCs with whom we spoke. Solomon (2011) peripherally mentions caregivers' research responsibilities associated with the initial inquiry as well as the fact that they have in-facility information seeking interactions with IPCs. These findings from Solomon's ethnographic study, though not a central part of his analysis, parallel some of our own research findings. Kangas' (2010) ethnographic research into the travel of Yemeni patients to other countries for private medical care confirms the centrality of family members in making the initial decision to access care abroad and their knowledge brokering roles. Kingsbury et al. (2012, p.371) state that caregivers sometimes need to assume essential decision-making responsibilities and that unanticipated changes in medical tourists' health status can force them to "navigate shifting boundaries of...[their] roles." Two autobiographical narratives written by caregivers about their journeys abroad with medical tourists offer the strongest source of confirmation of the findings reported herein (Grace, 2007; Rose, 2009). Both authors disclosed their active participation in all three of the roles identified here. Indeed, these former informal caregivers engaged in most of the responsibilities attributed to each of the knowledge broker, companion, and navigator roles (see Kingsbury et al., 2012 for greater analytic discussion of these narratives). With the findings of this article, we assist with putting discussion of caregiver activities and responsibilities from these other sources into context by explicitly considering the roles to which they are contributing.

The existing informal caregiving literature demonstrates that there are indeed commonalities between the roles filled by medical tourists' caregivers and those adopted by other types of informal caregivers. Much of this literature is focused on the practice of informal caregiving in the home (e.g., Bevan & Pecchioni, 2008; Connor et al., 2003; Lam, 2006; Molloy et al., 2005; National Alliance for Caregiving & AARP, 2004; Ussher et al., 2011). One difference between these caregivers and those discussed in this article is the person who serves as a first point of contact and ongoing informational resource. For medical tourists' caregivers it is the IPC, whereas homecare nurses often serve in this capacity in 'conventional' (i.e., local, non-transnational, long-term) informal caregiving in the home (Mezey, 2004; Neufeld & Harrison, 2010). Furthermore, our findings reveal that medical tourists' caregivers sometimes arrange lodging and tours and transfer documents to and from the destination country, whereas these are not common activities for non-transnational caregivers (Donelan et al., 2002; National Alliance for Caregiving & AARP, 2004; Ussher et al., 2011). Differences such as these can be attributed to the specific context of care (i.e., local vs. transnational care and familiar vs. unfamiliar environment). The greatest overlaps between roles undertaken by medical tourists' caregivers and other types of caregivers come in relation to non-context-dependent functions, such as facilitating information transfer and engaging in symptom monitoring. Many studies of informal caregiving in the home have found that informal caregivers in this setting play a pivotal role in transmitting details on changes in patients' health status to formal health care providers, keeping logs of symptom changes, and other similar activities (Donelan et al., 2002; Petronio et al., 2004; Sinding, 2004; Weinberg et al., 2007). There are also cases in which the specific activities undertaken by medical tourists' caregivers are different from those of conventional informal caregivers but the overall roles being enacted are identical. For example, finding a wheelchair to aid in a medical tourist's mobility in an airport is likely done with the same intent as arranging for a patient's accessible transit pick-up at home, a common activity undertaken by caregivers in other contexts (Donelan et al., 2002; National Alliance for Caregiving & AARP, 2004); in both cases the caregiver functions as a navigator.



### **2.4.1. Future Research Directions**

Although we provide the first dedicated investigation of the roles of informal caregivers in medical tourism, this article contributes only a small part to our understanding of them. We have not measured the frequency with which each role is adopted, we have not assessed the spatiality or temporality of these roles, nor have we considered the effectiveness of these roles in ameliorating or maintaining patient health or wellness or even offsetting what is known as ‘caregiver burden’. These all serve as important directions for future research. For example, the collective impact of the stressors encountered by informal caregivers in the practice of care is referred to as caregiver burden (Lee & Singh, 2010; Ray & Street, 2011; Roth et al., 2009). Significant burden might lead to ‘caregiver burnout’ (Lee & Singh, 2010; Murphy et al., 2007; Takai et al., 2011; Yilmaz et al., 2009). In this article, we show that the friends and family members who accompany medical tourists abroad are indeed filling informal caregiving roles and it would be valuable to determine if and how the activities they undertake in their capacities as knowledge brokers, companions, and navigators result in exposure to burden and ultimately burnout. This knowledge could then be used to assist in identifying interventions to offset that burden if it is found to exist. The caregiver group could benefit from, for example, the development of informational tools that anticipate and address the possibility of caregiver burnout. Although there has been some discussion of the need to create reliable, evidence-informed informational tools about medical tourism and enhance patients’ access to such sources (Lunt et al., 2010; Penney et al., 2011), there has been no consideration of whether or not medical tourists’ informal caregivers could similarly benefit from enhanced access to credible information. Second, any demonstration of burden or burnout among this group would contribute new evidence to the health equity debates that exist around the practice of medical tourism that focus on discerning who ‘benefits’ and who ‘loses’ from the existence of this health services trade (see, for example, Chen & Flood, 2013; Johnston et al., 2010). Although informal caregivers are not addressed in contemporary analyses of the health equity effects of medical tourism, they need to be incorporated into examinations of this subject.

An important area for future research pertains to our participant group: IPCs. An enhanced understanding of the scope and scale of IPCs' roles and responsibilities as a whole is very much needed. Such knowledge is critical given that many aspects of informal caregivers' roles hinge on the time, energy, and attentiveness of IPCs. Yet, there is not an adequate understanding of IPC training regarding interactions with caregivers, or the proportion of their time allocations or work tasks assigned to dealing with such interactions. Furthermore, we have shown that IPC and informal caregiver roles intersect at many points in a medical tourist's journey. The implications of these intersections for the roles assumed by each group are unknown, such as the benefits and drawbacks for the health and wellbeing of the medical tourist. Such research would not only be important in increasing the knowledge of caregiver roles and responsibilities, it would also expand the existing knowledge of relationships between other medical tourism stakeholder groups. Dedicated attention to IPC roles and responsibilities could, for example, be used to create a schematic that demonstrates the intersection of the roles of IPCs, formal health care providers, other staff from the medical facility and from hospitality services such as hotel concierges and airline representatives, caregivers, and medical tourists.

#### **2.4.2. *Limitations***

This analysis has some limitations. First, although interviewing IPCs is useful, it results a second-hand perspective on medical tourists' informal caregivers. We believe that the strengths of interviewing this group, particularly that they were able to comment on trends across many caregivers, outweighed this limitation. However, our analysis needs to be complemented with first-hand accounts from caregivers, and we intend on doing this in the next phases of our research. Second, the linguistic diversity of participants was limited. The primary interviewer's ability to speak only two languages with fluency, French and English, disqualified potential participants who were not fluent in either, although one Spanish-language interview was accommodated. Third, unspoken insights that may have been learned through the interviews were missed because they were not conducted face-to-face. The reliability and affordability of phone and Skype

interviews (see Laws et al., 2003) outweighed this concern as conducting interviews using this medium is what enabled us to recruit such an international sample of participants.

## **2.5. Conclusions**

We found that the friends and family members who accompany medical tourists abroad engage in caregiving roles almost continuously. They facilitate and supplement the efforts of formal health care providers at medical tourism facilities to ensure the patient's health and wellbeing and shoulder some of the responsibilities that might otherwise be assigned to patients. In this way, caregivers can act as both amplifiers and buffers: they amplify the efforts of the facility staff through facilitation and supplementation while buffering medical tourists from stresses stemming from responsibilities, anxieties, and discomforts. Although there are parallels between some of our findings about caregiver roles and those shared in the existing caregiving literature, the unique transnational care context of informal caregiving in medical tourism reveals activities and responsibilities assigned to particular roles that are specific to this particular care practice.

We believe that the knowledge that has been gleaned about a heretofore-neglected medical tourism stakeholder group, namely patients' informal caregivers, and the roles filled by members of this group provides valuable insight into how the medical tourism industry operates. Given the integral roles that friends and family members play, the practice of medical tourism and thus the industry that supports it seems highly dependent on their unpaid care work. As with other informal caregivers, these individuals are effectively overlooked "shadow workers" (Armstrong et al., 2001) – unpaid, untrained, and largely unrecognized care providers - in what is often reported as a highly lucrative industry. We believe that adopting this critical perspective in light of the findings is essential to effectively addressing the ultimate inequities created by medical tourism.

Although this question is far beyond the scope of this article, we do demonstrate the value of considering the roles that every stakeholder group plays in enabling this global health services practice. Without doing so, it becomes impossible to effectively determine the impacts of medical tourism, mitigate the negative ones, and enhance the positive ones, which is a key issue currently being discussed in research and policy circles (Connell, 2013; Forgione & Smith, 2007; Hopkins et al., 2010; Johnston et al., 2010; Lunt et al., 2012).

### **3. “You’re dealing with an emotionally charged individual...”: An industry perspective on the challenges posed by medical tourists’ informal caregiver-companions<sup>\*</sup>**

#### **3.1. Background**

Medical tourism involves patients travelling abroad to obtain non-emergency private medical care outside of established cross-boarder care arrangements (Connell, 2013; Lundt et al., 2011). Because this medical care is private, usually the patient covers the costs of treatment and travel out of pocket (Connell, 2013; Ehrbeck et al., 2008). Individuals engage in medical tourism for a variety of reasons, including the desire to: obtain procedures not available in their home country, save money on procedures that are not covered by their government or private health insurance, and avoid long wait times for procedures in their home countries (Carrera & Bridges, 2006; Eggertson, 2006; Mattoo & Rathindran, 2006; Milstein & Smith, 2006). Medical tourists from varied socio-economic backgrounds travel from a myriad of countries to obtain procedures in destination countries that are correspondingly diverse (Connell, 2013; Hopkins et al., 2010; Kangas, 2007). Another noteworthy feature of this globalizing health care industry is that friends and family members often accompany medical tourists abroad (Connell, 2013, Hopkins et al., 2010; Kangas, 2007; NaRanong & NaRanong, 2011; Yu JY, Ko, 2012). They may adopt a supportive role during the planning stages, while abroad, and upon return home, and are referred to here as caregiver-companions. In this article we

<sup>\*</sup> Casey, V., Crooks, V.A., Snyder, J., & Turner, L. (2013). “You’re dealing with an emotionally charged individual...”: An industry perspective on the challenges posed by medical tourists’ informal caregiver-companions. *Globalization and Health*, 9, 31.

shed light on caregiver-companions' central role as actors and stakeholders in medical tourism.

Little is known about caregiver-companions in medical tourism and the roles they take on in this global health services practice. In our previous research, it was found that they are an important part of many Canadian medical tourists' experiences at home and abroad (Crooks et al., 2011). Despite this, no dedicated research attention has been given to this group. The only published works that offer any depth of insight into the experiences of caregiver-companions are two biographical novels about medical tourists' journeys written by their caregiver-companions, though in both novels the authors focus heavily on the medical tourists' experiences and only somewhat on their own (Grace, 2007; Kingsbury et al., 2012; Rose, 2009). Some industry reports (eg. Medical Tourism Association, 2009; Travers et al., 2008) and academic studies (eg. NaRanong & NaRanong, 2011; Yeoh et al., 2013; Yu & Ko, 2012) have also attempted to quantify the number of friends and family members who accompany medical tourists abroad, though these pieces do not offer an experiential perspective on caregiver-companions. Otherwise, we have little understanding of the roles played by caregiver-companions, the benefits and challenges they introduce as stakeholders in medical tourism, and the risks they may incur while abroad, among many other aspects of their experiences.

It is important to have a better understanding of caregiver-companions because they embody the informal caregiving (i.e., unpaid care by untrained individuals) component in the medical tourism industry. Research consistently shows that informal caregivers - usually patients' friends and family - play a key role in maintaining patients' health and wellness (Bevan & Pecchioni, 2008; Molloy et al, 2005; Wright et al., 2010). While a competent caregiver may improve a patient's health, one who is less prepared and supported may be detrimental to it (Cook et al., 1997; Mittelman et al., 2006). Providing informal care can also have a negative impact on the health of the caregiver. For example, informal caregivers are susceptible to caregiver burden due to stress and burnout, which can present as anxiety, depression, and other mental health issues (Borg & Hallberg, 2006; Carretero et al., 2009; Hawranik & Strain, 2007; Lee & Singh, 2010;

Pinquart & Sorensen, 2003; Rocha Pereira & Rebelo Botelho, 2011; Roth et al., 2009). Having access to meaningful supports such as information or respite care providers, however, can assist with preventing the onset of such burden, and lead to a more positive caregiving experience (Commission on the Future Health Care in Canada, 2002; Friedman et al., 2009). In this paper, we provide a glimpse into the unique practice of transnational informal caregiving in the context of medical tourism.

The existing literature has served to show that there are many actors or stakeholder groups that, together, enable the practice of medical tourism. Patients receive care while surgeons and other physicians provide it, facilitators aid with connecting patients to hospitals and making travel bookings, and policy-makers and government officials work to ensure that destination countries have adequate infrastructure to receive these bookings (Birch et al., 2010; Martínez Álvarez et al., 2011). International patient coordinators (IPCs) constitute yet another such group. They are professionals who work at or with medical tourism destination facilities to coordinate the on-site care of medical tourists. Among many other activities, they often create itineraries for patients and serve as a point of contact for questions or concerns. Their responsibilities typically begin before a patient's booking is secured and continue until after a patient has returned home. Here we examine informal caregiving in medical tourism from the perspective of IPCs. This allows us to obtain a breadth of insight, which is a prerequisite for research on depth of experience. Out of any other medical tourism stakeholder group apart from the medical tourists themselves, IPCs have the most interaction with each caregiver-companion. In fact, it is usual for IPCs working in larger facilities to meet hundreds of caregiver-companions every year, which heightens their knowledge of trends among this medical tourism stakeholder group. It is for this reason that in the current article we examine facets of the caregiver-companion experience from the perspectives of IPCs. By interviewing IPCs from a range of medical tourism destination facilities across several countries, herein we are able to offer insights that have emerged from IPCs' interactions with many hundreds if not thousands of caregiver-companions and medical tourists alike.

In this article we present the findings of an analysis that examines the challenges that caregiver-companions can pose to IPCs, destination medical tourism hospitals/clinics and their staff, medical tourists, and even themselves from the perspectives of IPCs. It is important to note that the majority of IPCs we spoke with encouraged medical tourists to bring a friend or family member abroad with them because they commonly provide help and companionship which, they observed, positively affects medical tourist well-being. However, they also identified challenges that can be introduced with the presence of caregiver-companions. We believe that articulating these challenges helps to shed light on issues posed by the practice of informal caregiving in the global health services practice of medical tourism and the presence of caregiver-companions in destination facilities. To accomplish this, in the section that follows we outline the study design. Following this, we present the findings of a thematic analysis that identifies three characterizations of the challenges that caregiver-companions pose, in that they can: (1) require time, attention, and resources; (2) disrupt provisions of quality care; and (3) be exposed to risks. We then move to offer a discussion that contrasts the findings of the thematic analysis against existing findings in the medical tourism and informal caregiving literatures while also offering comments on directions for future research.

### **3.2. Methods**

This analysis is one component of a larger multi-method study. The purpose of the multi-method study is to gain an understanding of the experiences of Canadian medical tourists' caregiver-companions through gathering and analyzing their first-hand accounts and those of other stakeholders. Stakeholder groups consulted in the study are: Canadian medical tourists, Canadian medical tourists' caregiver-companions, Canadian medical tourism facilitators, and IPCs in various countries. In this paper, we focus exclusively on the IPC dataset. It is important to note that although the larger study to which this analysis contributes has a focus on outbound medical tourism by Canadians, the IPCs we interviewed were not asked to comment specifically on Canadian patients, but instead spoke of broad trends about all the caregiver-companions with whom they



have interacted. IPCs are an important participant group for our study objective, which is to obtain a breath of understanding of the challenges caregiver-companions can present, because they have interacted closely and persistently with, collectively, thousands of caregiver-companions throughout their careers as IPCs.

### **3.2.1. Recruitment**

Recruitment commenced upon receiving approval for the study from the Research Ethics Board at Simon Fraser University. Following receipt of this approval, we sought to recruit IPCs from a diverse range of countries and facilities to participate in phone and Skype interviews. Our target sample size was twenty, which is the number of IPCs we anticipated needing to speak with in order to achieve purposeful diversity in the sample. We used several methods to recruit participants, namely: (1) emailing letters of invitation to hospitals whose websites mentioned IPCs, IPCs found in online medical tourism directories, and IPCs who had posted on online forums; (2) snowballing out from existing participants; and (3) disseminating calls for participants through our team's networks and online forums and magazines. All emails and advertisements included the interviewer's contact information and indicated that interviews could be conducted in English or French (a request for a Spanish-language interview was also accommodated).

Upon receiving responses from potential participants, they were emailed a study information sheet and eligibility was confirmed. Eligibility required that participants were indeed IPCs and were based in or worked with medical tourism clinics or hospitals that offered surgical procedures that did not involve third parties (e.g., organ transplantation). Not all potential participants used the job title IPC, therefore we accepted only those who indicated that in their jobs they were present in the facility with the medical tourist, made care and other arrangements, and assisted clients in a non-clinical capacity. In order to enable as much diversity among the sample to be captured, no more than 3 people from a single facility were interviewed. For those who met these eligibility requirements, an interview was scheduled at a time of their convenience.

### 3.2.2. *Data collection*

Telephone and Skype interviews were conducted from July to October, 2012. Interviews were semi-structured in order to ensure that core issues were consistently probed and to allow participants to introduce topics that captured unanticipated experiences and insights. To ensure consistency, the first author conducted all the interviews apart from one. That interview was with a Spanish-speaking participant and was conducted by a knowledgeable collaborator.

All phone interviews started by obtaining verbal consent, in which confidentiality to the furthest extent of the law was assured. Verbal consent was chosen over written consent to minimize the logistical difficulties inherent in the international scope of our study. Interviews generally lasted from 45 to 75 minutes. As shown in Figure 1, they covered a range of topics: (1) caregiver-companion characteristics, (2) interactions between caregiver-companions and hospital staff, (3) caregiver-companions' roles and responsibilities, and (4) the risks to which caregiver-companions can be exposed. Data collection stopped when our target sample size was met, which coincided with the time our recruitment strategies ceased to generate interest from new potential participants.

**Table 1: Selected interview questions**

<b>Question</b>	<b>Sub-Probes</b>
What do you see as your role with regard to travel companions?	- How much interaction do you typically have with patients' travel companions? - What are some of the reasons that you interact with travel companions?
What kinds of responsibilities do you commonly see travel companions taking on?	- How prepared do you think travel companions are to take on these various responsibilities? - Are there any things you think could be done to assist with preparing them for these responsibilities?
What health and safety risks, including stressors, do travel companions face?	- Which of these risks has the most significant impact? - Who assists travel companions with minimizing these risks?

### **3.2.3. Analysis**

All interviews were recorded digitally and transcribed verbatim. Thematic analysis was employed, which involved six steps. First, the transcripts were reviewed by all investigators. Second, the team met face-to-face to discuss emerging themes as well as outliers. Third, themes that were collectively agreed upon were used to create a preliminary coding scheme by the first and second authors. The coding scheme identified umbrella concepts and their components into which data segments were categorized to inform thematic analysis (Schwandt, 2007). Fourth, transcripts were coded by the first author using NVivo qualitative data management software, with input on code refinement being sought from the second author. Fifth, emerging trends and patterns relevant to the themes pursued in the current analysis were identified in the coded data by the first and second authors. Sixth, these trends and patterns were then compared to existing knowledge and the study objectives by the first and second authors and confirmed by the full team to reveal a refined interpretation of meaning in coded data (Fereday & Muir-Cochrane, 2006). Importantly, common themes emerged through this process despite differences in participant work environments and work histories, which is a characteristic of thematic analysis (Braun & Clarke, 2006).

### **3.3. Findings**

We conducted 20 interviews with 21 IPCs (one interview had two participants). The participants worked at 16 different facilities across Bolivia, Costa Rica, Barbados, Mexico, the United States, Croatia, Turkey, Israel, India, and Thailand. Twelve of these facilities often received medical tourists from North America, six commonly saw Europeans, one saw mostly Australians, another saw mostly Africans, and two did not have a dominant region of origin for medical tourists. Some specialized in procedures such as cosmetic surgery, bariatric surgery, orthopaedic surgery, oncology procedures, spinal surgeries, veinoplasty, and cardiac surgery, while others provided a myriad of procedures.

At the time of the interview, the length of time participants had been IPCs ranged from six months to 12 years. Five participants worked for companies that were based outside of the hospitals or clinics that they coordinated care for, 12 worked for independent facilities, and four worked for hospital chains. Six were the only IPC employed by their company or facility while 15 worked in IPC teams. The IPCs we interviewed took on a range of responsibilities towards medical tourists. For example, three commonly helped the patient determine an appropriate surgeon and facility, thirteen coordinated the itinerary (e.g., surgical date, days of hospital stay, local accommodations, etc.) and ground transportation (e.g., transport to and from the airport, local transport for the caregiver-companion), fourteen routinely provided education to the patient and the companion, two provided some limited nursing care to the patient, and all answered questions and addressed requests.

In the remainder of this section we discuss the three themes that emerged from the dataset regarding the challenges that IPCs, international facilities, and medical tourists can face when caregiver-companions accompany a medical tourist, namely that: (1) companions require time, attention and resources, (2) companions can disrupt the provision of quality care, and (3) companions can be exposed to risks. It should be noted that, according to the majority of IPCs, the help and companionship that caregiver-companions commonly provide outweigh these challenges and caregiver-companion accompaniment is therefore recommended. We have included verbatim quotations throughout the section in order to enable the participants to ‘speak’ to these thematic findings. Following each quote we indicate the country in which the IPC participant was based as well as the number of years they had worked in this capacity.

### **3.3.1. *Caregiver-companions can require time, attention, and resources***

IPCs pointed out several ways in which the involvement of a caregiver-companion can serve to burden medical tourists. First, “*the costs are bigger when you travel with somebody of course, double airplane ticket, double accommodation, double meals, everything*” (Croatia, 2.5). In other words, there is a financial cost to bringing a

caregiver-companion. Second, a caregiver-companion may unintentionally increase the time needed for recovery by creating additional stress for the patient. This can be a consequence of worry or anxiety because “...if the [caregiver-companion] worries a lot then the patient is getting worried too and as you know the emotional state of the patient is really important for their recuperation process or their healing process...” (Costa Rica, 0.6). Third, caregiver-companions can further be burdensome by doing nothing at all. In these cases, the companions accompany the patient to the destination country, but are otherwise absent from the medical tourism experience. One participant commented that some of “the companions they feel that they are here on holiday so the patient is at the hospital themselves” (Thailand, 6). Participants suspect that this neglect is not intentional; rather, the companions do not understand the full scope of what is expected of them.

Although the patient is the focus of IPCs’ responsibilities, in nearly all cases coordinators also reported the need to attend to caregiver-companions and in doing so divert some of their time and attention away from the medical tourist. For example, they provide guidance when needed. If the companion’s presence is stressful to the patient, they may suggest a tourist activity: “...in the event that we find that the patient is uncomfortable... we try to, to get... the companion to go somewhere [like]... an island tour or a nice restaurant” (Barbados, 2). More often, IPCs will need to educate caregiver-companions regarding what to expect during the medical tourism process and what roles they should play. Education is an integral part of the participants’ self-identified role towards the companions. It is often cited as a strategy to avoid stress from the medical tourist, the companion, and the facility staff: “the more educated the companion, [the] better [it is] for all of us” (Turkey, 1). The companion may initiate this education by asking questions. One participant noted that companions are “always very, very worried, full of... maybe unnecessary questions... most often the companions of the patient are more worried and more, more, more curious than the patient himself” (Croatia, 2.5). Some caregiver-companions also voice complaints about the facility, the doctor, or about the burden of their own worries. In the latter case, IPCs comfort them: “...you’re dealing with an emotionally charged individual to begin with and they have

*different expectations... and it takes a great deal of time and attention to calm them down”* (Thailand, 12). Like educating the companion, many IPCs saw offering comfort as strategically important to a positive experience and, although doing so took time, there were eventual benefits to be had from this time investment.

Caregiver-companions can create a redundancy of some roles with staff in medical tourism facilities. Many perform the hands-on care normally done by nurses, such as by helping the medical tourist with every day tasks after surgery while still in the facility. *“They assist the patient to get up and go to the bathroom, even though the nurses are available to do that... The same as showering, bathing, the nurse is completely capable of doing that but a lot of times the travel companion wants to do that instead”* (Mexico, 12). They also often help with recovery exercises, namely for mobility, and monitor the patient for symptom changes. The responsibility of offering comfort to the patient is sometimes adopted by the companion instead of facility staff because they are familiar and usually constantly at the patient’s side. Caregiver-companions will also communicate with loved ones back home, a task that many IPCs are prepared to do. One participant said that *“some have their own GATT connection or Skype in their computers. And so [I say] ‘I can make an international call for you’. And they say ‘No, I don’t need that. I brought my own equipment. I brought my Skype, I brought my jack, I brought this. I came prepared”* (Costa Rica, 5). Although these redundancies are seemingly helpful in that they free up the time of facility staff, IPCs indicated that they can pose challenges to continuity in symptom monitoring as well as record keeping.

### **3.3.2. Caregiver-companions can disrupt the provision of quality care**

Workers at medical tourism hospitals and clinics, and IPCs specifically, can find it challenging to accommodate companions because they do not always respect facilities’ norms. For example, facility rules occasionally need to be changed in light of disruptions the companions introduce to the organizational routine. According to one participant, their facility needed to change the protocol regarding the number of visitors that patients could have in their room at once. The change occurred after the arrival of a patient’s

seven companions who “*overran the facility*” (USA, 8). Multiple participants noted that companions often complain about the food on behalf of the patient. In one case, a companion insisted that s/he prepare the patient’s food in the facility’s kitchen. As the participant recounts: “*we have even allowed the attendants of the companion to enter the kitchen and prepare their own kind of food with their own hands*” (India, 2.25). While it is the norm that caregiver-companions provide support and some hands-on care to the patient, in some instances this was not done. For example, in some cases the companions “*passively support*” (Thailand, 6) patients, meaning that they are physically present but they do not adopt any other caregiving responsibilities. Other companions are perceived as uncaring and absent from the bedside. These two types of disruption, exceptional caregiver-companion actions (e.g., insisting on preparing food for the patient) as well as unexpected inaction (e.g., offering only passive support), both create more work for facility staff and disrupt facility norms.

Facilities are sometimes faced with companions who enable patients to go against the advice given by staff and clinicians. Prior to arrival in the destination country, it is important for the patients to follow instructions in preparation for the surgery or to provide accurate information about their health status. This advice is, however, not always followed. Participants noted that in some cases caregiver-companions were complicit in this problematic behaviour. Then, in cases where physicians cancel the procedure as a result, companions can become upset (Thailand, 12):

*I: Are there any exceptional or unusual cases of companions accompanying medical tourists that stick out in your mind?*

*P: Yes there are several, usually it’s misinformation from the patient side. Patients who are HIV positive, who... [have] other underlying problems and they present for a simple procedure and you find out that they have a heart condition and many other things, there are major problems and you can’t treat them... So you turn them away [after they have arrived].*

*I: ...How do the companions react to this?*

*P: ...Often outrage, because they’ve [caregiver-companions] been part [of it]...they [patients] think they can go to another country and get treatment for various things they’ve probably been turned down for in their own country.*

Other caregiver-companions may believe that their competence is equal or superior to that of the nurses and physicians, and as a result do not act on clinical advice. This can present as over-protectiveness: “*sometimes the travel companion can be a little bit too over-protective and they think they know better than the doctor*” (Mexico, 1.5 & 0.75). They may also enable patients to ignore or act against facility rules such as those regarding smoking on the hospital or clinic grounds. Thus, caregiver-companions can enable patients to ignore rules and clinical instructions, and also avoid following them themselves.

Some IPCs reported on cases in which caregiver-companions were required to make decisions on clinical advice on behalf of the medical tourists. In the cases of caregiver-companions with limited financial resources, the financial affordability of medical care may inform decision-making and can override clinical advice and best practice, particularly in light of complications that require quick decisions and significant financial resources. One participant told the story of a caregiver companion he worked with (Turkey, 1.5):

*Somebody's dad is in the ICU [intensive care unit] and...there were complications. You have to extend your dad's stay in the ICU, you don't know what's going to happen, and so cost just increases and increases. But you never really thought of ...such a long stay and such an expensive hospital particularly in the ICU which... without insurance is a tremendous cost. And so it was a very difficult situation for them I think both financially, emotionally: and 'how far do you go, how much is your dad worth?' that was really the question.*

Caregiver-companions with limited financial resources may be faced with unanticipated financial challenges on top of the already debilitating cost of medical tourism.

### **3.3.3. *Caregiver-companions can be exposed to risks***

According to the IPCs we spoke with, caregiver-companions can be exposed to stress, which is a health risk, at a number of points throughout the course of a medical tour. The majority of participants noticed that before the patient has had surgery,



companions typically experience stress from worry about the outcome of the procedure. *“I would say a little bit stressful... Once the patient’s out and everything is okay they seem to be okay”* (Thailand, 1.5). Another reason for the stress is a lack of trust in the country, the facility, and/or the IPC experienced by some caregiver-companions. One participant summed it up as *“...the stress factors [are] the fears, the prejudice, judgments toward the country, towards the hospital, [and] treatment procedures”* (Turkey, 1). However, these stresses usually fade once caregiver-companions gain some understanding of the country and the hospital environment, and, according to many participants, a large part of the IPCs’ interactions with the companions pre-surgery involves fostering this understanding. Participants also noted that during this time, IPCs often try to educate the companions on the procedure and care plan, as well as the ways in which the companions could be helpful to the patient. This helps to remove the stress associated with feeling unprepared, which is common amongst caregiver-companions who *“really have no clue what’s happening”* (Turkey, 1.5). As one participant noted *“when the patient and the companion are informed about what’s going on they’re... more calm”* (Costa Rica, 2.5). Therefore, education and information are used to minimize or avoid stress.

After surgery, distinctive types of stresses are commonly experienced among caregiver-companions. Multiple participants reported emotional strain in companions due to worry for the patient, stress over an unknown outcome, and uncertainty of their role in assisting with the patients’ pain management and overall wellbeing. One participant noted that *“sometimes [we] will actually have a companion that would be more on verge of a breakdown than the patient because they take such responsibility in the whole situation, wanting everything to be perfect, wanting the patient not to be in pain”* (Thailand, 6). It may also be difficult for caregiver-companions to handle the sight of swelling and surgical wounds immediately after a surgery, especially one that is cosmetic or bariatric in nature. However, the inability to handle this among caregiver-companions can create more stress for the patients and can slow their healing process. Therefore IPCs who work in facilities that offer cosmetic and bariatric procedures exclusively commonly advise patients to travel unaccompanied (Bolivia, 7):

*Companions bring more stress to [patients]... Let's say, one of the stitches comes out early and you have never seen open stitches before, and... you can see inside the [patient] and they get really scared. So [companions] make the patient more stressed out than if [companions] are not there [with them] .... We actually do not advise them to come with a companion.*

Many participants characterized companions as worried, and therefore at risk of experiencing stress, because they are constantly anxious about the patient's welfare. Although the stresses may overlap, there are distinctions between pre- and post-surgery stresses. Before surgery, as discussed in the last paragraph, companions are concerned about trusting their environment as well as their own competencies, which can cause stress. After surgery, their focus tends to be strongly focused on the patients, which can lead to worry and therefore mental stress and anxiety.

Companions can face safety risks, some of which can also threaten their health, while abroad. Participants noted that companions and medical tourists alike may be robbed, financially exploited, get lost in the city, or drink contaminated tap water. IPCs will sometimes educate caregiver-companions to about the potential travel risks to help mitigate them for the companion as well as the patient (Croatia, 2.5):

*During the stay in Croatia they can be robbed... they can get lost in the different countries... the patient coordinator will instruct the companion what to do...how to behave in certain countries because the cultures are different, the things are different in each country... so I think the communication between the coordinator and the companion and then with the patient is crucial.*

Risks associated with everyday life are also present while caregiver-companions are abroad. Participants recounted their experiences with companions who were in a bar fight, had fallen down a flight of stairs, were in a car accident, experienced a heart attack, and become ill with a stomach flu while abroad. One participant said: “we had a companion who went on a hike and broke her leg” (Israel, 3). Given the range of risks that caregiver-companions may be exposed to while abroad, both within the facility and beyond, it is impossible for IPCs to anticipate the full scope of risks.

### **3.4. Discussion**

The findings shared above show that, according to IPCs who have spent many hours interacting with and addressing challenges caused by tens to perhaps thousands of caregiver-companions throughout their careers, caregiver-companions and the practice of informal caregiving can present multiple challenges to international medical tourism facilities, their staff, and even to medical tourists. Despite this, the IPCs we spoke with were overwhelmingly supportive of caregiver-companions accompanying medical tourists abroad, with the exception of some who worked with patients receiving bariatric or cosmetic surgeries, because caregiver-companions were perceived to be more valuable overall than challenging. However, they do present challenges. The IPCs pointed out that caregiver-companions may, for example, have a negative impact on the patient through cost of accompaniment or inadequate care provision. Caregiver-companions may also create unanticipated or extra work for IPCs and other workers in destination facilities as additional clients and by ignoring established organizational rules, routines, and expectations. Furthermore, caregiver-companions may be susceptible to stresses and health and safety risks, which can further deteriorate their own abilities to offer the patient quality care. Our findings show that IPCs believe companions are more successful caregivers and less of a burden to staff when they are receptive to education from IPCs and willing to act upon it. Our findings also show that the presence of a caregiver-companion can shift the IPC's focus from the patient to the companion at times. Building on these findings, in this section we contrast what this study has found about the challenges that caregiver-companions can pose against findings in the existing informal caregiving and medical tourism literatures. Doing so enables us to offer some insight into what is distinct about transnational informal caregiving in the medical tourism context.

Our analysis has revealed that caregiver-companions require additional resources. Medical tourist often shoulders the financial burden of an extra flight, accommodation and meals when they travel accompanied. For that reason, cost can be an issue of relevance to caregiver-companions' involvement in medical tourism, a point that was

voiced by most IPCs we spoke with. Although other studies have shown that cost can be an important factor in medical tourists' decision-making (Cohen, 2010; Garud, 2005; Glinos et al., 2006; Leng, 2007; Horowitz & Rosensweig, 2007; Yu & Ko, 2012) because it may be less costly to obtain a procedure abroad than at home (Burkett, 2007; Glinos et al., 2006; The Gallup Organization, 2007), discussion of cost savings in medical tourism rarely mention the costs associated with bringing a caregiver-companion. In other words, the cost incentive associated with obtaining medical care abroad may be brought into question for those accompanied by a caregiver-companion; a point that is paralleled in some other medical tourism studies that have emphasized the heavy financial burden that can be placed on medical tourists and their families, and particularly those traveling from the Global South (Johnston et al., 2012; Kangas, 2007). Our analysis further shows that caregiver-companions with less financial resources are equally motivated by cost when put in the position of having to make decisions based on clinical advice while abroad, especially when complications occur. This finding echoes concern in the existing medical tourism literature about the role that cost plays in medical tourists' making decisions based on clinical advice (Cheung & Wilson, 2007; Turner, 2007a; Turner, 2007b).

Our findings show that when caregiver-companions travel abroad, they may be exposed to risks and stresses derived from the unknown and unfamiliar nature of their surroundings. Caregiver-companions may even be apprehensive about the medical tourism facility and mistrust the standards of care. This is consistent with media reports of a popular schema about poor care quality and standards in developing countries\* (Casacchia, 2010; Martin, 2009; Meyer, 2009; Russell, 2007). According to IPCs, such apprehension can lead caregiver-companions to disrupt a facility's organizational routines due to mistrust or misunderstanding, which can have significant implications for facility staff and even the medical tourist. Caregiver-companions may also hold pre-existing stereotypes or misconceptions about cultural norms that inform their

\* Medical tourists from developing countries perceive the opposite: the local standard of care is seen as inferior whereas the foreign one is held on a pedestal (Kangas, 2007).

apprehensions. This point is consistent with the findings of other studies that have pointed out that medical tourists may have concerns regarding the “foreignness” of the destination they are travelling to (Grace, 2007; Howze, 2007; Mudur, 2004). Meanwhile, our study also shows that caregiver-companions’ own apprehensiveness over “foreignness” and the unknown may lessen their abilities to address these same concerns held by medical tourist. The unfamiliar environment of care is the main difference between caregiver-companions and conventional informal caregivers who provide care locally and mostly in the home. Conventional caregivers are not burdened by the apprehension of “foreignness”, nor are they predisposed to doubt the quality of local facilities where they spend a minority of their time as caregivers. The need to travel to a foreign facility introduces additional challenges for caregiver-companions, and therefore patients and facility staff, that are not otherwise experienced.

The findings of our study show that caregiver-companions are often needy, in that they require time, attention, and resources, and that IPCs attempt to address these needs. IPCs are available by telephone while the companions and patients are abroad, and they are often physically present while the patient is in the hospital to assist with meeting these needs. While the support, advice, and information they provide to caregiver-companions may seemingly present as extra work, the IPCs that we spoke with viewed it as an intervention aimed at minimizing stress, burden, and other negative outcomes for caregiver-companions, the medical tourist, and facility staff. This aspect of the IPC’s role, in relation to supporting the caregiver-companion, is consistent with the findings of other studies that have shown that medical tourism facilities tend to have significant staffing resources and provide a high amount of interpersonal time dedicated to patients (Connell, 2006; NaRanong & NaRanong, 2011; Solomon, 2011). Attentiveness towards caregiver-companions by IPCs can take the form of providing guidance, education, and comfort in order to be responsive to their needs. The provision of education in particular may assist with overcoming what is often reported to be the lack of reliable information available to those engaging in medical tourism (Lunt & Carrera, 2010; Lundt et al., 2010). Although information being shared by an IPC as an educational strategy to meet caregiver-companions’ needs and avoid the onset of stress is unlikely to be neutral - a

concern raised about the pervasiveness of industry-generated information being used to inform decisions about medical tourism (Eysenbach, 2001; Johnston et al., 2012; Lunt et al., 2010) - the reportedly trusting relationship built between the companion and coordinator may enhance its perceived trustworthiness.

Multiple studies have shown that having access to meaningful formal support for informal caregivers, such as that provided by IPCs in the context of medical tourism, can translate into increased health and wellbeing for the patient (Northouse, 2012; Surbone & Baider, 2012) and caregiver alike (Carretero, et al., 2009; Hawranik & Strain, 2007; Mangan et al., 2003; Rocha Pereira & Rebelo Botelho, 2011). The findings of our research confirm that, in the experience of our participants, support in the form of dedicated collaboration between the companion and the IPC is necessary to improve patient outcomes and avoid a slowed recovery. However, researchers and policy-makers have been quick to point out that there is a difference between having access to support and the uptake of this same support, and that some informal caregivers are simply not accepting of assistance in any form (Bass et al., 1996; Weinberg et al., 2007). IPCs seem to be cognizant of this and they offer support actively and intentionally as a strategy to elucidate a better experience for the medical tourist, the companion, and hospital staff. This suggests that caregiver-companions in medical tourism may be equally in need of being prompted to accept support in order to minimize their stress and burden as other types of informal caregivers.

Informal caregivers typically experience more stress when they are not able to effectively collaborate with health professionals (Bucher et al., 2001; Egerod & Overgaard, 2012; Morse & Pooler, 2002; Northouse et al., 2012; Weinberg et al., 2007). Similarly, our findings show that when caregiver-companions are thought to not be open to collaborating with medical tourism facility staff, and most specifically the IPC, it is more difficult for them to carry out their caregiving responsibilities and they may find the experience more stressful. Participants, for example, reported that companions can be incapable of or ineffective at helping patients if they are too worried about surgical outcomes or their own care abilities. Worry is also a sign of caregiver burden (Jacobs,

2004; Rocha Pereira & Rebelo Botelho, 2011; Wolpe, 2004) and, not surprisingly, some IPCs identified it as a potential source of stress and negative health outcomes for caregiver-companions. Our findings have also shown that worry is very common throughout the companion's time abroad and can sometimes negatively impact the patient who, according to other medical tourism studies, may already be experiencing stress (Howze, 2007; Janevic & Connell, 2001; Law, 2008).

### ***3.4.1. Directions for future research***

While our analysis sheds new and dedicated light on the challenges introduced by caregiver-companions in medical tourism, and also on the roles and responsibilities more generally associated with this stakeholder group, we believe that much research remains to be done about the intersection between medical tourism and informal caregiving. Our findings have shown some differentiation between caregiver-companions as a result of socio-economic status and the procedure the patient is obtaining abroad, but it is unclear if there are meaningful differences between them based on their relationship with the medical tourist, their country of origin, or the destination country, and what these differences may be. Meanwhile, some of these differences have been found to be extremely important to caregiver health status and patient outcomes in other forms of informal caregiving (Dentinger & Clarkberg, 2002; Janevic & Connell, 2001). Our analysis also suggests that the presence of caregiver-companions and the actions they undertake can be beneficial to the health of the patient, and that support from IPCs is beneficial to caregiver-companions and thus ultimately the patient. However, we require more knowledge regarding the other forms of support caregiver-companions draw from or that they require. For example, would caregiver-companions benefit from gaining access to some or all of the interventions developed for informal caregivers in various health systems and governments, such as system navigation tools, support groups, and therapeutic interventions (Commission on the Future Health Care in Canada, 2002; Rizzo et al., 2011)? This is a pressing question that researchers can assist with answering.

This analysis helps to demonstrate the value in speaking with stakeholders in medical tourism who are knowledgeable about other stakeholder groups, and particularly groups that are difficult to locate (as is the case with caregiver-companions). In particular, it highlights the potential for having IPCs serve as participants in medical tourism research. Our findings have shown IPCs' perspectives on the challenges introduced by caregiver-companions, but a counter-point to this, examining the benefits they introduce for IPCs and other destination facility staff would be a useful direction for future research. Our findings have further shown that the extra expense of travelling abroad with a friend or a family member may discourage some medical tourists from taking a companion. However, research has hinted at the regularity with which friends and family members accompany medical tourists abroad (Kangas, 2007; NaRanong & NaRanong, 2011; Yeoh et al., 2012). A detailed account of the reasons for which they are perceived as useful enough to justify the extra expense has yet to be undertaken. IPCs would be ideal participants for such a study for the same reasons that we found them helpful for our own: they have the most interaction with the highest number of companions out of any stakeholder group that we are aware of and they can therefore speak to the breadth and depth of a particular issue relevant to those they interact with in a professional capacity.

#### **3.4.2. *Limitations***

First, recruitment information indicated that interviews could be conducted in French and English. Upon request of an interested potential participant, we were able to coordinate a Spanish-language interview as well. IPCs who were not fluent in these languages were not included in this study. Second, the utilization of semi-structured phone and Skype interviews may have resulted in some missed data due to the inaccessibility of visual cues and the formality of the conversation. Studies have shown, however, that phone interviews are a reliable and cost effective method for data collection (Laws et al., 2003), and for this reason we are confident in the soundness of the dataset. Third, in this analysis we have considered many aspects of the caregiver-companion's experience in medical tourism, yet we did not consult with a single



caregiver-companion in doing so. While we believe that our use of IPCs to gather information about this stakeholder group is well justified, it is nonetheless a limitation that we present information about caregiver-companions here solely from the perspective of IPCs. A clear direction for future research, including our own, is to speak with caregiver-companions themselves about the experiences embedded in the current analysis along with other aspects of their informal caregiving roles and responsibilities.

### **3.5. Conclusions**

In this article, we presented the findings of a thematic analysis derived from 20 interviews with 21 IPCs working in 16 medical tourism facilities across nine countries. We examined concerns that these IPCs identified regarding the challenges that caregiver-companions and the practice of informal caregiving may pose to facility staff and medical tourists. These concerns include the potential for caregiver-companions to be exposed to health and safety risks that negatively impact not only themselves but also the medical tourist. It was also shown that caregiver-companions can be burdensome to medical tourism facility staff, including the IPCs, through requiring time and attention in order to minimize or lessen anxiety, worry, and ultimately stress. IPCs tend to actively take steps to mitigate the potential for challenges to arise in relation to informal caregiving in medical tourism, with a particular focus on caregiver-companion education. Our findings suggest that if companions are open to collaboration with IPCs, and particularly in the form of information sharing, then their experience abroad can be safer and less stressful for themselves and, by extension, for the accompanied patients and facility staff.

This article has positioned caregiver-companions as a central stakeholder group in the global health services practice of medical tourism and has also shown the value of asking one stakeholder group, namely IPCs, about their experiences with another, namely caregiver-companions, to gain broader knowledge. Most broadly, the analysis shed light on the very practice of informal caregiving in medical tourism, which is a particular form of transnational caregiving – a form of caregiving that has received little dedicated

research attention. Caregiver-companions represent the intersection between medical tourism and informal caregiving and, to our knowledge, this is the first account that focuses on this intersection. We encourage more research to be done so that informal caregiving in medical tourism can be further examined and also so that appropriate responses to and interventions for this transnational caregiving practice can be implemented.

## **4. Conclusion**

### **4.1. Introduction**

I have presented two analyses in my thesis. Together, they make up the first stage of a three-stage study whose aim is to establish a firm understanding of the roles and responsibilities of Canadian caregiver-companions, a group that was previously ignored in medical tourism research. Since there is no existing academic literature that focuses explicitly on caregiver-companions, this first stage situates the global caregiver-companion stakeholder group within the medical tourism industry and among other stakeholder groups. I have done so by analyzing the retrospective experiences of another stakeholder group, international patient coordinators (IPCs), with caregiver-companions to provide a broad industry perspective. This broad scope creates an equally broad foundation of knowledge on which other caregiver-companion research can be conducted, which is the intent of the research. By establishing a preliminary understanding of the caregiver-companion stakeholder group, my thesis is able to highlight the group as an important part of the medical tourism industry and to point the way for future medical tourism research. In this chapter, I will summarize the analyses conducted for my thesis, revisit the objectives I laid out for my research, discuss the key research contributions, and identify future areas of research that can build upon the knowledge generated in my thesis.

## 4.2. Summary

In the first analysis, I examined the roles taken on by caregiver-companions in providing care for medical tourists. According to its findings, caregiver-companions take on three distinct but overlapping roles. In the knowledge broker role, caregiver companions facilitate the transfer of information between patients, the facility staff, and others. In the companion role, they offer emotional and hands-on care. Finally, the navigator role is played when caregiver-companions coordinate the itinerary and travel plans, and handle documentation. These roles are very similar to those of conventional informal caregivers (Donelan et al., 2002; Petronio et al., 2004; Sinding, 2004; Weinberg et al., 2007) that have been shown to improve patient health (Bevan & Pecchioni 2008; Karimli et al., 2012; Molloy et al., 2005). The differences between the two are found in the context of care, which, for caregiver-companions, is transnational and unfamiliar rather than local. This similarity of roles, combined with the regularity with which caregiver-companions adopt the roles, their pervasiveness in the medical tourism industry (Connell, 2013; Kangas, 2007; NaRanong and NaRanong, 2011; Yeoh et al., 2013; Yu and Ko, 2012), and the proximity of the caregiver-companion to the medical tourist while abroad indicate that they are important providers of healthcare to the medical tourist. However, they are typically unacknowledged and unpaid. According to the informal caregiving literature, the roles they take on may lead to caregiver burden and burnout (Carretero et al., 2009; Rocha Pereira & Rebelo Botelho, 2011), which can in turn contribute to the list of health inequities identified within the medical tourism industry (e.g., Connell, 2013; Forgione & Smith, 2007; Hopkins et al., 2010; Johnston et al., 2010; Lunt et al., 2012). In sum, caregiver-companions' roles are varied and have implications for caregiver-companion health and the medical tourism industry.

My second analysis offers an industry perspective on caregiver-companions and the challenges that they may introduce while abroad. Although the bulk of IPC participants recommended accompaniment, the findings identify three problematic areas associated with it, in that caregiver-companions can: (1) require time, attention, and resources, (2) disrupt the provision of quality care, and (3) be exposed to health and

safety risks. Some of the challenges faced by caregiver-companions identified in this thematic analysis reflect the literature that discusses those faced by medical tourists, namely the high cost of engaging in medical tourism (Johnston et al., 2012; Kangas, 2007) and discomfort with unfamiliar surroundings (Grace M, 2007; Howze, 2007; Mudur, 2004). Additional stress may be experienced by medical tourists whose caregiver-companions behave in a way that does not prioritize them as targets of care; the expense of an extra person abroad may not then be justified to the medical tourist. The stress and worry that caregiver-companions were regularly reported to experience while abroad, moreover, might pose the risk of caregiver burden and burnout (Jacobs 2004; Rocha Pereira & Rebelo Botelho, 2011; Wolpe, 2004), among other risks associated with travel and everyday life. Meanwhile, medical tourism facility staff stress can sometimes stem from the creation of extra work and the disruption of routines. However, many IPCs view this extra work as an intervention to foster collaboration between facility staff, caregiver-companions and medical tourists that smoothes many of the other challenges identified in the findings. The informal caregiving literature agrees with this approach because it identifies staff-caregiver collaboration as the ideal kind of interaction between them for patient and caregiver health alike (Bucher et al., 2001; Egerod & Overgaard, 2012; Morse & Pooler, 2002; Northouse et al., 2012; Weinberg et al., 2007). This analysis broadly found that the challenges that present themselves with the introduction of caregiver-companions as a stakeholder group are varied but do not necessarily cancel out the benefits they can bring.

Together, the analyses represent the first academic attempt to focus specifically on caregiver-companions and to establish their place as stakeholders within the medical tourism industry. Both analyses suggest that caregiver-companions are important contributors to medical tourists' health. Even those who are otherwise challenging, as discussed in Chapter 3, can provide valuable care by acting as anchors to the familiar for medical tourists, which may help to reduce their stress level. When the stresses involved in providing informal care in the context of medical tourism are kept in check, caregiver-companions can be helpful to facility staff and medical tourists alike. Caregiver-companions can facilitate communication between staff and the medical tourist, provide

multiple forms of comfort and hands-on care, and handle the trip planning details. When they are not adding to it, they are perceived to alleviate patient stress and worry by taking whatever roles they can on behalf of or for the patient, which often require interaction with other stakeholder groups such as formal health care providers and other facility staff (also seen in Grace, 2007; Rose, 2009; Solomon, 2011).

IPC involvement as intermediaries between caregiver-companions, facility staff, and medical tourists is instrumental to the successful execution of many caregiver-companion roles, and was highlighted in both analyses. IPCs understand that interaction between themselves and caregiver-companions is, rather than an additional source of stress, often useful to the medical tourists, the facility staff, the caregiver-companion, and themselves. By being accessible to caregiver-companions for questions or concerns, they facilitate the integration of caregiver-companion roles with the facility rules and routines while maximizing patient care. In short, IPCs enable collaboration between informal caregiver and formal health care provider roles, a feat often advocated for in the informal caregiving literature (Bucher et al., 2001; Egerod & Overgaard, 2012; Morse & Pooler, 2002; Northouse et al., 2012; Weinberg et al., 2007). The analyses suggest that caregiver-companions can, with IPC facilitation, work with formal health care providers in medical tourism facilities towards their mutual goal of securing patient health, and can minimize stresses for all involved. IPCs thus help caregiver-companions to perform their roles while minimizing challenges, and they appear to be useful links between medical tourism stakeholders including caregiver-companions.

Although caregiver-companions perform useful roles, they are subject to stress and worry while abroad. The informal caregiving literature labels this as caregiver burden and burnout (Jacobs, 2004; Rocha Pereira & Rebelo Botelho, 2011; Wolpe, 2004). Caregiver burden is associated with a decrease in patient health (Tooth et al., 2005; van Exel, 2005), while appropriate support for informal caregivers, which lessens caregiver burden, has been linked to increased patient health (Northouse et al., 2012). This means that caregiver burden acts as an obstacle to the performance of caregiver roles, but the roles can be continued with appropriate support. The risk of caregiver

burden and burnout are discussed in both analyses and, based on its heavy emphasis in the informal caregiving literature, it is likely that caregiver-companions experience some level of it despite IPC presence. Burden or burnout may therefore serve as a barrier to caregiver-companions' integration within the industry by preventing the effective execution of their roles.

### **4.3. Revisiting the Objectives**

My thesis had two objectives. The first objective was to explicate how caregiver-companions balance multiple roles and responsibilities. Chapter 2 lists a great variety of roles they might perform, especially while abroad, and the findings of both analyses suggest that caregiver-companions may not balance these roles and responsibilities well. Indeed, many may avoid some or all of the roles identified in the first analysis. Those who do perform at least some of the roles - this appears to be the vast majority of caregiver-companions - seem to commonly experience stress as a result, which can lead to caregiver burden. Perhaps this is because their persistent and extreme proximity to patients pressures them to take on roles more often than they would otherwise. However, it appears that IPCs often offer them support and can act as guides throughout the experience, which may limit the impact of this stress and help them to balance their roles. Although research from the point of view of the caregiver-companions is needed for confirmation, my thesis suggests that, overall, caregiver-companions struggle to effectively balance their multiple roles.

The second objective of my thesis was to determine the health and safety risks to which caregiver-companions may be exposed through the process of transnational caregiving. Several health and safety risks to caregiver-companions were identified in the analyses. The most significant of these is the stress that accompanies caregiving roles as discussed above, which can lead to caregiver burden and burnout. It is very common

for caregiver-companions to be worried about patients' health and wellness for different reasons throughout the medical tourism journey. As above, the findings in my thesis require confirmation from research that poses similar questions to caregiver-companions themselves, but caregiver-companions are likely exposed to multiple health and safety risks through their caregiving roles.

#### **4.4. Research Contributions**

The analyses in my thesis used the input of third party stakeholders, IPCs, rather than the stakeholder group of interest, caregiver-companions. By doing so, my thesis was able to capture experiences with a much larger segment of this stakeholder group than it would have by asking caregiver-companions directly about their roles and responsibilities. It also enabled me to situate the target stakeholder group within the medical tourism industry by viewing caregiver-companions in relation to IPCs. This is a useful strategy for future medical tourism research that aims to establish a base understanding of any under-researched stakeholder group. Medical tourism is an industry in which many of its stakeholder groups regularly interact with each other, and can therefore be valuable sources of information about one another. IPCs are especially useful because they mediate interactions with formal and informal caregivers, and their administrative role may lend them insight into the stakeholders groups involved with the administration of medical tourism facilities. My thesis demonstrates that obtaining data from participants outside of the group being studied can be an effective strategy in medical tourism research.

The successful application of geographic concepts and ethical theories to health research is found throughout my thesis. As quoted in the introduction, health geography “explores how and why people's health and access to health care vary from place to place” (McLafferty, 2010) and, in this case, the health care that is being explored is provided in countries where patients and caregiver-companions do not reside. Both



analyses contrast the spaces of care of caregiver-companions, who provide the bulk of their care abroad, with those of conventional informal caregivers, those who provide care in a local context (e.g., the private home). In this way, the application of geographical concepts such as ‘transnational care’ is ideal for this study. Furthermore, my thesis relies on a concept that is regularly used by health geographers when investigating healthcare: an ethics of care approach (Milligan, 2009; Milligan & Wiles, 2010; Herron & Skinner, 2012; Williams, 2011). Because the ethics of care framework makes the assumption that all care providers have a responsibility of care to those who need it (Held, 2006; Parton, 2003; Tronto, 1993), my thesis reflects the presumed spirit among caregiver-companions and medical tourism facility staff that prioritizes patient health. I have therefore been able to maintain a focus on the strategies used by caregiver-companions (and IPCs) to promote patient health. By bringing geographical concepts and ethical theories to health research, I have been able to identify and address an issue that was previously ignored, doing so in a way that streamlines the framework of care.

#### **4.5. Future Research Directions**

Although my thesis helps to expand academic knowledge of caregiver-companions, it also introduces new questions about them that can be answered with further research. As with much research, the reliability of the qualitative findings presented herein can be enhanced through triangulation by quantitative analysis (Bryman, 2004). It is unclear, for example, how many caregiver-companions take on which of the roles identified in Chapter 2. Furthermore, are some roles favoured by certain demographics of caregiver-companions? What is the breakdown of caregiver-companion demographics in terms of country of origin, gender, and relationship to the medical tourist, all of which have been shown to impact the care provided among other informal caregivers (Dentinger & Clarkberg M, 2002; Janevic & Connell, 2001)? Moreover, my thesis assumes that these roles are mostly helpful to the medical tourist, but confirmation of this is beyond its scope. A quantitative comparison of the health outcomes and self-rated health of medical tourists who were accompanied against those who were not would

be needed to confirm the assumption. Caregiver-companion demographics would be useful to consider here as well because it is possible that the care provided by some demographic groups yields inferior results concerning medical tourist stress, recuperation, and/or long-term health, and should therefore be targeted for more education. In general, quantitative analysis, including caregiver-companion demographics, would be helpful to complement and confirm (where possible) the qualitative findings of this thesis.

Although quantitative research is necessary, further qualitative study of medical tourists' caregiver-companions is also required. My thesis analyzes the observations of those who work most closely with caregiver-companions, IPCs, to understand them. The subjective experience of caregiver-companions therefore remains unknown. Subjective analysis would be a meaningful complement to my thesis because it can offer valuable insight into real-world issues (Siegesmund, 2008) such as caregiver-companion needs, which could then inform government, industry, and individuals' decisions concerning caregiver-companions and medical tourism as a whole. The next stage of the larger study to which these analyses contribute involves interviews with former caregiver-companions to obtain data on this subjective experience, although retrospectively. There is therefore an existing plan to address this knowledge gap. Subjective analysis could further extend into the emotional geographies of caregiver-companions, as hinted at in Kingsbury et al. (2012), which would be valuable given the reoccurring theme of stress throughout the analysis.

My thesis notes that significant support is provided to caregiver-companions by IPCs while they are abroad. According to the informal caregiving literature, support is key to avoiding caregiver burden and burnout (Carretero et al, 2009; Hawranik & Strain, 2007; Mangan, et al., 2003; Rocha Pereira & Rebelo Botelho, 2011), but it must be meaningful to the recipient (Bass et al., 1996; Weinberg et al., 2007). It is unknown if caregiver-companions consider the support offered by IPCs to be meaningful and therefore adequate for minimizing their risk of exposure to burden or burnout. Additional sources of support that were not considered in my thesis might also be drawn upon, and

that relative meaningfulness of those supports is likewise unknown. It is also possible that caregiver-companions would benefit from additional sources of support that they cannot currently access and that require government or industry resources, such as reliable informational material (something that is scarce even for medical tourists (Lunt et al., 2010; Penney et al., 2011)). Further research into their needs could reveal the full support network available to caregiver-companions, its effectiveness, and the gaps therein.

#### **4.6. Importance**

I contend that caregiver-companion research is important in order to advance the state of knowledge on medical tourism. Such research can reveal health benefits associated with medical tourist accompaniment, and, conversely, identify the barriers. Caregiver-companions spend the majority of their time abroad in close proximity with medical tourists, and they likely influence the quality of their health. For example, they may increase or decrease medical tourists' stress levels or provide high to low quality of hands-on care. Furthermore, the health of caregiver-companions themselves is potentially compromised. As shown in Chapter 3, risks may be incurred throughout the medical tourism experience including: caregiver burden and burnout, worry about the patient, and risks associated with travel and everyday life. However, caregiver-companions need to be recognized as an important and valuable medical tourism stakeholder group before these risks can be addressed or mitigated, or before caregiver-companions can be integrated as providers of quality health care to medical tourists. My thesis is therefore important and timely because it draws attention to caregiver-companions and encourages further research to be conducted.

My thesis demonstrates that caregiver-companions are an important medical tourism stakeholder group. As discussed in Chapter 2, they facilitate the provision of

patient care by facility staff, provide hands-on care, and ensure that patients follow clinical instructions, thereby amplifying the efforts of facility staff towards medical tourists. Caregiver-companions also buffer the patient from stresses related to unfamiliarity, discomfort and trip details. Chapter 3 further situates caregiver-companions in the network of medical tourism industry stakeholder groups and highlights the importance of acknowledging their unpaid care work routinely and early on to avoid later challenges. Their presence may be an asset to medical tourists and facility staff, an encumbrance, or both, but it is always felt. Caregiver-companions are therefore an important medical tourism stakeholder group and they deserve the attention of researchers and decision-makers. My thesis is the first to deliver this much-needed attention.

## **4.7. Conclusion**

The medical tourism industry is in its nascent stages, and its complexities are still being revealed. Its stakeholder groups, for example, have been unevenly studied. Some groups obtain far more research attention than others of equal importance such as its informal caregivers, here called caregiver-companions. These are the friends and family members who accompany medical tourists abroad (Connell, 2013; Kangas, 2007; NaRanong and NaRanong, 2011; Yeoh et al., 2013; Yu and Ko, 2012). While abroad, caregiver-companions are nearly always in close proximity to medical tourists and perform caregiving roles almost constantly, some of which they are uniquely positioned to take on. They also adopt caregiving roles before departure and after return home. Although their pervasive presence approaches that of medical tourists, caregiver-companions are not commonly acknowledged as important medical tourism stakeholders.

Caregiver-companions' contributions are often obscured in discourse because medical tourism is routinely framed as a multi-billion dollar industry (Connell 2006; Connell, 2013; Herrick, 2007; Hopkins et al., 2010; Lunt et al., 2012; Ramírez de Arellano 2007; Terry, 2007) rather than one with unpaid workers. As the

industry's "shadow workers" (Armstrong et al., 2001), caregiver-companions offer various kinds of care to medical tourists without payment or acknowledgement. They are therefore imperfectly integrated into the industry, which can create challenges for them and other medical tourism stakeholder groups. This reality was demonstrated in my thesis. Integration in the form of collaboration with medical tourism facility stakeholder groups is key to bringing them recognition and to minimizing the challenges they can present. It could also minimize the risks to caregiver-companions by creating meaningful support (Carretero et al., 2009; Hawranik & Strain, 2007; Mangan, et al., 2003; Rocha Pereira & Rebelo Botelho, 2011). I believe that caregiver-companions must be figuratively brought out of the shadows and incorporated into the standard medical tourism caregiving practices to maximize their positive contribution to the medical tourism industry.

Decision-makers in government and industry need to acknowledge caregiver-companions along with medical tourism facility staff, as well as the roles these groups can play in ensuring patient safety. They can implement policies that integrate medical tourists' friends and family members as caregivers and that offer them support where they need it. For example, government decision-makers may extend the benefits offered to its conventional informal caregivers to caregiver-companions if it is found that such benefits can offset stress, burnout, or burden. Similarly, those in the industry could train facility staff to work collaboratively with them or offer services tailored to their needs. Decision-makers could also commission the creation of informational resources specifically for caregiver-companions (Lunt et al., 2010; Penney et al., 2011). Although not enough is known about caregiver-companion needs to implement these policies, my thesis illuminates the path. It puts a spotlight on these pervasive shadow workers and calls for a greater understanding of them for their own benefit and for that of that of the medical tourism industry as a whole.

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